Living with chronic pain following a pain management programme

Robin Muir

Supervised by:

Dr. Gundi Kiemle

Dr. Rebecca Simm

Submitted in partial fulfilment of the Doctorate in Clinical Psychology

University of Liverpool

Acknowledgements

I would like to thank everyone who has contributed to this thesis. Most importantly, I thank Jenny for her constant confidence and belief in this work over the past three years, her patience has been astounding and is greatly appreciated. Thanks also go to my family and friends who have supported me while I have completed this work. I appreciate the support of my supervisors, Dr. Gundi Kiemle and Dr. Rebbeca Simm, who allowed me the independence to develop, but also provided guidance when I needed it. I would also like to thank Dr. Bill Sellwood for reading drafts of this thesis and his constructive feedback. I also sincerely appreciate the support of Southport and Ormskirk Community Pain Service for helping to recruit participants. Finally, I would like to acknowledge the participants who took part in this study and were willing to share their experiences. Their accounts of chronic pain have not only shaped this work, but also my own understanding of what it means to live with pain.

Table of contents

List of Tables

List of Figures

List of Appendices

Word Count (excluding references): 24, 979

Introduction: Thesis Overview

Chronic pain is pain that has lasted for longer than six months (B. H. Smith, Elliott, & Hannaford, 2004) and has a wide ranging impact on individuals' lives, affecting physical, social and psychological functioning (B. H. Smith et al., 2001). Despite the impact of chronic pain and the significantly increased use of healthcare (Von Korff, Wagner, Dworkin, & Saunders, 1991), the effectiveness of treatments for chronic pain are limited to a minority of individuals, whether of a medical or psychological orientation (Turk, 2005). One approach to chronic pain is through pain management programmes, which aim to increase individuals' quality of life, psychological functioning and levels of activity (British Pain Society, 2007). Although previous reviews of the effectiveness of pain management programmes have concluded that such programmes are effective (Eccleston, Williams, & Morley, 2012; Flor, Fydrich, & Turk, 1992; Scascighini, Toma, Dober-Spielmann, & Sprott, 2008), these reviews have focussed on the short-term (less than 12 months) outcomes. Considering that such programmes do not ameliorate pain and that individuals will often experience pain for the rest of their lives there is a need for review of the long-term outcomes of these programmes. Paper one of this thesis is a review of the quantitative literature concerning long-term (greater than 12 months) psychological and quality of life outcomes of pain management programmes.

Whilst quantitative research concerning chronic pain has focussed upon the short-term effectiveness of psychological treatments, qualitative research has focused upon the experience of chronic pain prior to interventions (Hellström, 2001; J. A. Smith & Osborn, 2007; Toye et al., 2013). In particular, this research has highlighted themes relating to a changing understanding of individuals' bodies and a threat to their identity (Hellström, 2001; Osborn & Smith, 2006; J. A. Smith & Osborn, 2007; Toye et al., 2013). As there is now greater certainty of the effectiveness of psychological approaches to chronic pain (Eccleston, Williams, & Morley, 2012) there is currently a shift away from studies of the effectiveness of interventions to a greater focus upon the mechanisms of change (McCracken & Marin,

2014; Morley, Williams, & Eccleston, 2013). Qualitative research of living with chronic pain following pain management programmes would inform both clinicians' and researchers' understanding of the experience of living with chronic pain after an intervention and therefore contribute to the development of this area of research. It would also help to contextualise psychological models of chronic pain (Hayes, Strosahl, & Wilson, 2004; Vlaeyen & Linton, 2000) within a phenomenological understanding (J. A. Smith, Flowers, & Larkin, 2009). The second paper of this thesis aims to provide a phenomenological account of the experiences of participants who have completed a pain management programme 12-36 months prior to participating in the research.

References

British Pain Society. (2007). *Recommended guidelines for pain management programmes for adults*. London: The British Pain Society.

Eccleston, C., Williams, A. C. D. C., & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews,* (11)

Flor, H., Fydrich, T., & Turk, D. C. (1992). Efficacy of multidisciplinary pain treatment centers: A meta-analytic review. *Pain, 49*(2), 221-230.

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2004). *Acceptance and commitment therapy: An experiential approach to behavior change*. New York, US: Guilford Press.

Hellström, C. (2001). Temporal dimensions of the self-concept: Entrapped and possible selves in chronic pain. *Psychology and Health, 16*(1), 111-124.

McCracken, L. M., & Marin, F. M. (2014). Current and future trends in psychology and chronic pain: Time for a change? *Pain Management, 4*(2), 113-121.

Morley, S., Williams, A. C. D. C., & Eccleston, C. (2013). Examining the evidence about psychological treatments for chronic pain: Time for a paradigm shift? *Pain, 154*(10), 1929-1931.

Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. the experience of the body in chronic benign low back pain: An interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences, 20*(2), 216-222.

Scascighini, L., Toma, V., Dober-Spielmann, S., & Sprott, H. (2008). Multidisciplinary treatment for chronic pain: A systematic review of interventions and outcomes. *Rheumatology (Oxford, England), 47*(5), 670-678. doi:10.1093/rheumatology/ken021 [doi]

Smith, B. H., Elliott, A. M., Chambers, W. A., Smith, W. C., Hannaford, P. C., & Penny, K. (2001). The impact of chronic pain in the community. *Family Practice, 18*(3), 292-299.

Smith, B. H., Elliott, A. M., & Hannaford, P. C. (2004). Is chronic pain a distinct diagnosis in primary care? evidence arising from the royal college of general practitioners' oral contraception study. *Family Practice, 21*(1), 66-74. doi:10.1093/fampra/cmh115

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis*. London, UK: Sage Publications.

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health, 22*(5), 517-534.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). Patients' experiences of chronic non-malignant musculoskeletal pain: A qualitative systematic review. *British Journal of General Practice, 63*(617), e829-e841.

Turk, D. C. (2005). The potential of treatment matching for subgroups of patients with chronic pain: Lumping versus splitting. *The Clinical Journal of Pain, 21*(1), 44-55.

Vlaeyen, J. W. S., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain, 85*(3), 317-332. doi:http://dx.doi.org.ezproxy.liv.ac.uk/10.1016/S0304-3959(99)00242-0

Von Korff, M., Wagner, E. H., Dworkin, S. F., & Saunders, K. W. (1991). Chronic pain and use of ambulatory health care. *Psychosomatic Medicine, 53*(1), 61-79.

Long-term psychological and quality of life effects of pain management programmes: A systematic review [1]

Robin Muir[a], Gundi Kiemle[b]

[a]*Department of Clinical Psychology, University of Liverpool, Whelan Building , Brownlow Hill, Liverpool, L69 3GB, United Kingdom, rmuir@liv.ac.uk*

[b] *Department of Clinical Psychology, University of Liverpool, Whelan Building, Brownlow Hill, Liverpool, L69 3GB, United Kingdom, g.kiemle@liv.ac.uk*

Corresponding author:

Robin Muir
Department of Clinical Psychology
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool
L69 3GB

rmuir@liv.ac.uk

(+44) 0151 794 5534

Number of pages: 39

Number of figures: 1

Number of tables: 3

[1] To be submitted to: PAIN (no word limit, but a guide that no review should be more than 6000-8000 words is suggested) (see Appendix A)

Long-term psychological and quality of life effects of pain management programmes: A systematic review

Background: Pain management programmes are a multidisciplinary approach to the treatment of chronic pain. The evidence for their effectiveness in the short-term is strong, but synthesis of the long-term psychological and quality of life outcomes is lacking. This study aimed to conduct a review of long-term (12 months or longer) studies of the effectiveness of pain management programmes. **Methods**: A systematic search strategy of six databases and key references was conducted to identify controlled and uncontrolled studies reporting psychological and quality of life outcomes of pain management programmes. Primary outcome measures were psychological well-being and quality of life. Secondary outcomes on psychological processes were also extracted. **Results**: Twelve papers involving a total of 1,476 participants with chronic pain were included. Nine of the twelve papers found that significant improvements in psychological functioning or quality of life were maintained at long-term follow-up. A number of psychological processes were identified that were associated with significant improvement at long-term follow-up. There was significant variability in the quality of included studies, alongside significant heterogeneity in terminology and interventions within the research field of chronic pain making it difficult to synthesise results. **Conclusion**: The positive effects of pain management programmes upon psychological and quality of life outcomes are stable and maintained at long-term follow-up. There is a need for greater consensus between researchers to ensure that mechanisms through which pain management programmes are effective are understood.

Keywords: chronic pain; pain management; pain management programme; multidisciplinary: systematic review; cognitive behavioural therapy

1. Introduction

Chronic pain, defined as pain that has lasted for longer than six months [54], is one of the most common reasons people seek medical care and leads to a five fold increase in healthcare utilisation [70,71] and involves significant deterioration in physical, occupational, social and psychological functioning [53], increased distress [11,40] and reduced quality of

life [8]. This human and economic cost highlights the importance for healthcare services to respond effectively to the needs of people with chronic pain.

Psychological models of distress in chronic pain take a biopsychosocial perspective [59]. Two of these models, the fear-avoidance [69] and psychological flexibility [19] models, which have cognitive-behavioural foundations, have received particular attention. The fear-avoidance model suggests that individuals become trapped in vicious cycles of disability maintained by beliefs about pain, such as the inevitably of pain leading to disability. The psychological flexibility model on the other hand proposes that distress is maintained through overly rigid responses to pain, such as avoidance of activity or searching for amelioration. The development of these models has led to the proliferation of psychological approaches to the management of chronic pain, such as cognitive-behavioural therapy [42] and acceptance and commitment therapy [66]. Pain management programmes (PMPs) apply these approaches in groups and alongside other interventions, such as physiotherapy. Being delivered by multidisciplinary teams allows PMPs to meet the diverse needs that stem from the heterogeneity found in people who experience chronic pain, such as the diversity in the causes of chronic pain, location of pain, patient demographics, chronicity of pain and the clinical presentation of patients. This heterogeneity has been proposed as the reason that the effectiveness of a range of interventions, including medications, physical and psychological treatments, is restricted to a minority [58]. PMPs are underpinned by a self-management ethos [33]; they involve education on topics such as pain, self-management and unhelpful habits, alongside guided practice including exercise and goal setting [9].

In one of the first reviews of multidisciplinary approaches to pain management Flor et al. [15] found them to be more effective in improving pain, mood, disability, vocational status and health utilisation than no treatment, waiting list controls and non-multidisciplinary approaches. However, only ten of the included studies presented findings on mood, which was the only psychological outcome reviewed. In addition, the majority of studies used convenience sampling based upon patient preference or ability to pay for treatment, and the overall quality of studies was judged to be low. A further limitation was that the

understandings of chronic pain and management approaches have progressed significantly since it was published [59].

A more recent systematic review found strong evidence that multidisciplinary approaches with a total duration of 100 hours or more lead to improved function (i.e. less disability) and moderate evidence that they lead to reductions in pain [17]. However, this review did not examine psychological or quality of life outcomes. A third review found multidisciplinary approaches to be moderately more effective than single-discipline approaches and no treatment [51]. However, as Scascighini et al. [51] judged effectiveness by the presence of significant findings in two or more out of five outcome areas, it is difficult to draw conclusions on particular areas of functioning, such as quality of life or psychological functioning.

Although pain management approaches lead to improvement [13,17], this improvement is in the context of continuing pain; therefore there is a need to understand how stable the effects of PMPs are in the long-term. Of the three reviews mentioned above, Guzman et al. [17] did not review long-term effectiveness, Flor et al. [15] found effects to be significant at follow-up periods greater than six months, whilst Scascighnini et al. [51] found that only five of the 35 studies they reviewed provided information on long-term (greater than 12 months) outcome, but that effects were maintained. Scascighnini et al. [51] comment that their review was limited by only including randomised controlled trials as the ethical implications of withholding treatment prevent randomised controlled trials having long-term outcomes.

In conclusion, previous reviews of multidisciplinary approaches to pain management have been significantly limited by a lack of focus upon long-term effectiveness, a sole focus upon randomised controlled trials, and heterogeneity in how effectiveness is measured and in which domains of functioning. The heterogeneity in these reviews reflects the diversity in chronic pain research. Although positive in that this diversity has led to the proliferation of ideas and evidence, recently there have been calls for unification in this field and greater specificity in the definitions of psychological processes underlying outcomes [36,43].

Therefore, there is a need for reviews of psychological outcomes of PMPs and considering the long-term nature of chronic pain this should focus upon long-term outcomes. This study therefore aims to review the long-term impact of PMPs upon psychological functioning and quality of life.

2. Method

2.1 Eligibility Criteria

This review focuses on studies of quantitative long-term evaluations of the effectiveness of PMPs in terms of psychological and quality of life outcomes. Due to the difficulties of carrying out long-term randomised controlled trials (RCTs), both RCTs and prospective cohort studies were sought, therefore controlled and uncontrolled studies were included. To ensure that only studies evaluating the effectiveness of PMPs were included, interventions were assessed against the British Pain Society's recommendations on PMPs [9], which is also supported by European guidelines on PMPs [1]. Studies were only included if the intervention was underpinned by a psychological theory; the programme was facilitated by a multidisciplinary team with a core membership of a medical professional, physiotherapist, and psychologist (or other suitably qualified and supervised therapist); the programme had a focus on physical, psychological and social outcomes; the intervention involved education on a range of topics including pain mechanisms, the psychology of pain, and self-management of pain, and involved guided practice, underpinned by goal-setting. Studies were included if:

- due to the potential bias of studies involving small numbers [21], there was more than 20 participants in each arm of the trial;
- outcomes were reported from a 12 month or longer follow-up period;
- participants had non-malignant pain for more than six months;
- participants were aged over 18; and
- published in English.

Studies were excluded if:

- participants were selectively allocated to trial arms; or
- the study was of a retrospective design.

2.2 Search strategy

Publications were retrieved by searches of six electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Cochrane Central Register of Controlled Trials, PsychInfo, Medline, Scopus and Web of Knowledge. All databases were searched for studies from inception to April 2014. Furthermore, reference lists of related reviews [13,15-17,51,65] and included studies were reviewed. The flow of information is reported using the Preferred Reporting Items for Systematic Reviews (PRISMA) diagram (Figure 1) [41].

2.3 Search terms

The search terms used were broad to reflect the diversity in terminology used with this research area. Three concepts were represented by search terms and were combined using Boolean operators. The first concept related to the condition of chronic pain and included 'chronic pain*', 'persistent* pain', 'fibromyalgia', 'chronic low back pain', 'prolonged pain*', 'long*lasting pain*', 'continuing pain*', 'enduring pain*' and 'protracted pain*'. The second concept was pain management programmes and included 'pain management program*', 'pain program*', 'multidisciplinary pain*', 'interdisciplinary pain*', 'comprehensive pain*' and 'pain rehabilitation'. The final concept was the focus upon long-term outcomes and included 'long*term', 'follow*up', and 'longitudinal'.

2.4 Quality assessment

The final 12 papers were assessed using a scale designed specifically for quality assessment of trials of psychological interventions in pain [78], the results of which are presented in Table 2 below. Due to the inherent difficulty of the use of blinding in RCTs of psychological interventions a number of items are included to assess if attempts were made

to control for issues arising from lack of blindness, such as assessment of treatment expectations. There is also a six-item subscale relating to treatment quality, for example, whether treatment manuals have been used and level of therapist training, which tends to be missing from other quality assessment tools [78]. The second subscale, with 22 items, relates to methodological quality, such as, randomisation processes, outcome measures, and methods of analyses. Each item is rated from zero to either one or two. The scale was adapted for use with prospective cohort studies by removing items relating to group equivalence, randomisation, allocation bias, and type of control group used.

Whilst the total scores for the overall, treatment and study design quality are reported in Table 2 below, these scores should be approached with caution as total scores can obscure nuances in studies' quality. Particular strength in one methodological area can obscure important methodological weaknesses in other areas.

2.5 Data extraction

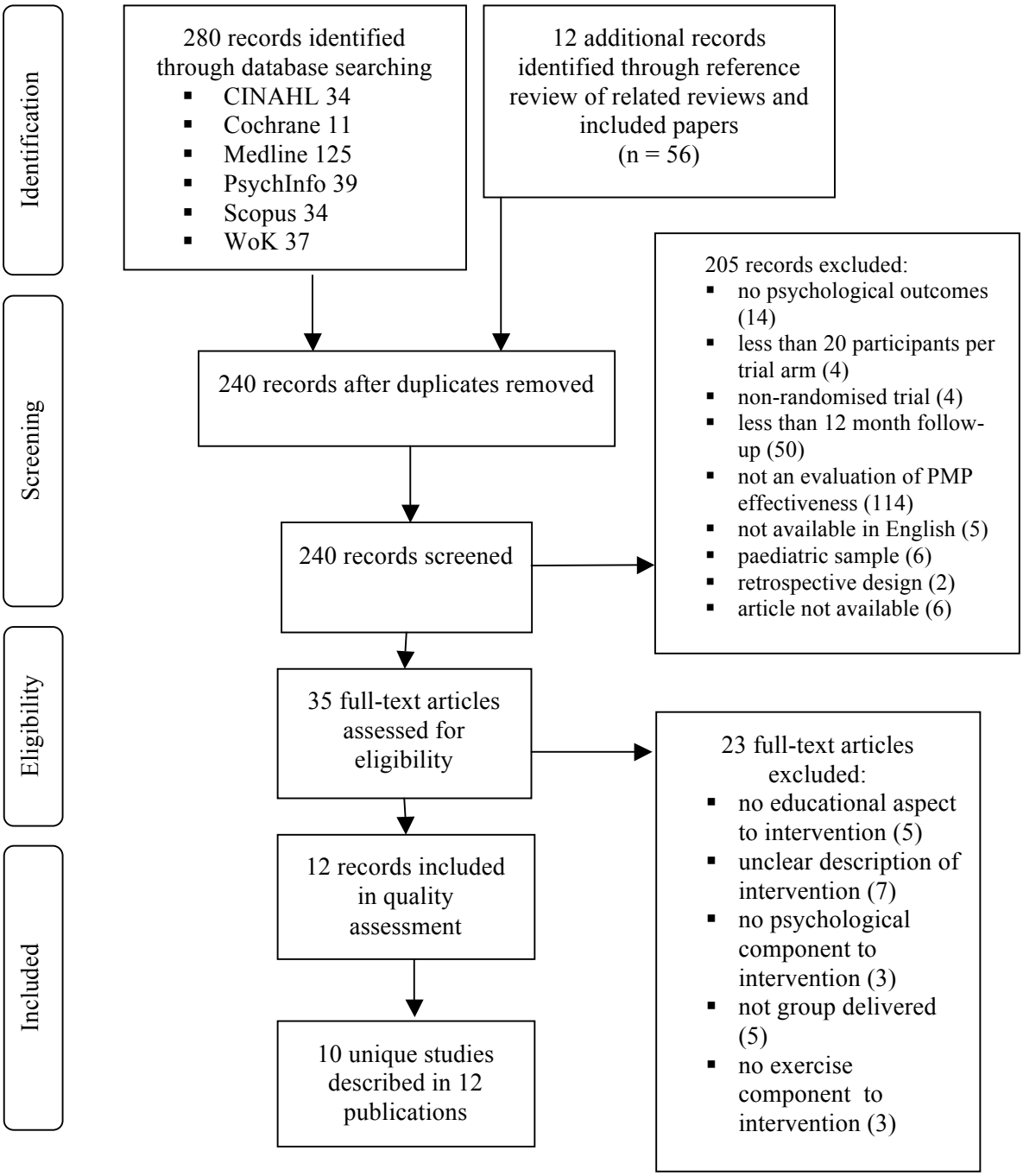
A data extraction form was developed and piloted before data extraction. Data were extracted on the study design, participants, intervention details, comparator details, outcome measures and details of analyses. In line with the Clinical Importance of Treatment Outcomes in Chronic Pain Clinical Trials (IMMPACT) recommendations [12,60], primary outcomes were psychological functioning and quality of life.

3. Results

A total of 228 records were obtained from the electronic search, and 52 duplicates were removed. A further 56 records were identified through searching references of included studies and related reviews. In total, 240 articles were assessed on title and abstract, with 35 being eligible for full-text assessment. Reasons for exclusion are given in Figure 1 below. The most common reasons were that the article did not report a study of the effectiveness of a PMP or that the follow-up period was less than 12 months. These 35 studies were then reviewed, with a further 23 studies excluded on the basis that the intervention being

investigated did not meet the British Pain Society's guidelines on PMPs. As two studies reported on long-term follow-ups of other included studies, the 12 records represent ten unique studies. One article [27] included two studies, one an RCT with a one-month follow-up and the other a prospective cohort study with a one-year follow-up; the former was excluded on the basis of its shorter follow-up period.

Figure 1. Flow of information through the different phases of the search



3.1 Characteristics of included studies

Details of the included studies can be found in Table 1 below (see Appendix B for information on content of PMPs). The ten studies involved a total of 1,476 participants. The mean age of participants ranged from 42 [27] to 81.9 [14], it should be noted that this latter study, although not purposively recruiting older participants, recruited from retirement communities. The majority of participants in all studies were female; in one study the authors retrospectively excluded the very small proportion (2%) of males from the analysis [28]. Most studies involved people with either chronic pain of any bodily site or specifically of the spine, whilst one study specifically recruited people with fibromyalgia [68]. Final follow-up period ranged from 12 months in five studies to 36 months in two studies.

3.1.1. Search strategy effectiveness

Of the 12 records included only two were found from the database search, with the remaining ten records being identified through review of reference lists of key references.

Table 1. Characteristics of included studies

Study	Study design	Country	n	Mean age (SD or range)	Female, %	Average duration of pain (months)	Pain type	Evaluation moments	Attrition rate %
Ersek (2008) [14]	RCT	USA	256	PMP: 81.9 (6.3) C: 81.8 (6.7)	PMP: 87.2 C: 82.1	X	Musculoskeletal non-cancer pain	Baseline, post-intervention, 6- & 12-month FU	PMP: 14.3 C: 16.3
Jensen (2001) [25]	RCT	Sweden	214	43.3 (10.4)	54.7	31.3	Non-specific spinal pain	Baseline, post-intervention, 6- & 18-month FU	PMP: 12.7 PT: 14.3 CBT: 14.3 C: 20.8
Jensen (2005) [24]- Follow-up to Jensen (2001)	RCT	Sweden	214	43.3 (10.4)	54.7	31.3	Non-specific spinal pain	36-month FU	PMP: 25 PT: 7 CBT: 28 C: 42
Kaapa (2006) [28]	RCT	Finland	132	PMP: 46 (7.9) C: 46.5 (7.0)	98*	I: 16 C: 14	Chronic low back pain	Baseline, post-intervention, 6-, 12- & 24-month FU	PMP: 17 C: 25
Turner-Stokes (2003) [61]	RCT	United Kingdom	126	PMP: 47.3 (10.1) C: 48.3 (12.3)	69	104.6	Chronic pain, no untreated pathology	Baseline, post-intervention, 12-month FU	PMP: 26 C: 26

Vlaeyen (1996) [68]	RCT	Netherlands	131	44 (9.4)	88	122.4	Fibromyalgia	Baseline, post-intervention, 6- & 12-month FU	PMP: 22 C: 23
Williams (1996) [76]	RCT	United Kingdom	121	IP: 48.7 (11.6) OP: 50.4 (11.7) C: 51.1 (10.7)	54	94	Chronic pain	Baseline, 1- & 12-month FU	PMP: 22 C: 22
de Rooij (2014) [10]	PCS	Netherlands	138	45.04 (10.3)	95	84	Chronic widespread pain	Baseline, 6- & 12-month FU	17.4
Johansson (1998) [27]	PCS	Sweden	85	42 (8.6)	68	132	Musculoskeletal	Baselines, 2- & 12-month FU	26-48
van Hooff (2010) [63]	PCS	Netherlands	107	44.1 (8.4)	57	144	Chronic low back pain	Baseline, post-intervention, 1- & 12-month FU	23
van Hooff (2012) [64]- follow-up to van Hooff (2010)	PCS	Netherlands	90	42.9 (8.4)	59	146.4	Chronic low back pain	12- & 24-month FU	5.6
Vowles (2011) [72]	PCS	United Kingdom	166	47.1 (10.7)	62	96	Chronic pain	Baseline, post-intervention, 3- & 36-month	34.1

Note: C- control group, CBT- cognitive behavioural therapy, FU- follow-up, IP- inpatient, OP-outpatient, PCS- Prospective cohort study, PT- physiotherapy RCT- Randomised controlled trial, X- no data reported

*Three males were retrospectively removed from the sample and analysis

3.2 Quality Assessment

Quality assessments of the included studies can be found in Table 2 below.

3.2.1 Treatment quality

The treatment quality scores ranged from three to eight, out of nine. Most studies provided a coherent rationale for the intervention being evaluated and described content well. It should be noted that as part of the inclusion criteria was based upon the content of the intervention, studies that did not meet this standard or did not describe content had been excluded. Overall, there was very little use of a treatment manual in the included studies, with only four studies [14,26,72,76] describing full manualisation. This was coupled with only four studies [14,24,26,72] reporting checks on adherence to treatment protocols. Therapist training was limited to a description of the professional qualification of therapists in all but two studies, which described specific therapist training [14,76]. Only two studies provided information relating to patient engagement, that is, whether the investigators took steps to check that patients engaged in the intervention, for example reviews of homework tasks and skills practice [26,76].

3.2.2. Design quality

3.2.2.1 Randomised controlled trials

Of the RCTs, overall scores varied from 16 to 30, out of 35. In particular, four studies provided very little detail about the processes used to randomly allocate participants to trial arms [14,61,68,76]. Only one of the six RCTs reported the use of an independent assessor to collect outcome data [76], meaning the collection of outcome data in other studies may have been biased. Only three of the studies used intention to treat analysis [24,26], which, considering the levels of attrition in included studies, highlights a significant limitation.

None of the included RCTs used an active control group that was well matched to the PMP, either in structure or its meaningfulness. Five studies [14,24,26,28,61] did use active treatment groups, but these were not well matched to the PMP, for example either being a component of a PMP, such as exercise, or bibliotherapy.

3.2.2.2. Prospective Cohort studies

Only two of the prospective cohort studies [63,64] described methods to reduce the biases in measurement, such as the use of an independent assessor. None assessed participants' expectations about the treatment and only two studies [63,72] used intention to treat analysis. However, three studies used power calculations [10,63,64] and all had appropriate sample sizes and used suitable analyses.

Table 2. Results of quality assessment using Yates et al's [78] assessment measure.

Item (Maximum total possible)	Ersek (2008)	Jensen (2001)	Jensen (2005)	Kaapa (2006)	Turner-Stokes (2003)	Vlaeyen (1996)	Williams (1996)	de Rooij (2014)	Johansson (1998)	van Hooff (2010)	van Hooff (2012)	Vowles (2011)
Treatment quality												
Description of treatment content[a]	2	1	2	1	1	2	2	2	1	1	1	2
Description of treatment duration[b]	1	1	1	1	1	1	1	1	1	1	1	1
Manualisation [a]	2	2	0	0	0	0	2	0	1	0	0	2
Adherence to a manual[b]	1	1	1	0	0	0	0	0	0	0	0	1
Description of therapist training[a]	2	1	1	1	1	1	2	1	1	1	1	1
Patient engagement[b]	0	1	0	0	0	0	1	0	0	0	0	0
Study design quality												
Sample criteria[b]	1	1	1	0	1	1	1	1	0	1	1	1
Evidence that sample criteria have been met[b]	0	1	1	0	1	1	0	0	0	1	1	1
Reporting of attrition[a]	2	1	2	2	2	1	1	2	1	1	1	1
Reporting of attrition rates[b]	1	1	1	1	1	1	1	1	1	1	1	1

Description of sample characteristics[b]	1	1	1	0	1	1	1	1	1	1	1	1
Assessment of group equivalence[b]	1	1	1	1	1	1	1	-	-	-	-	-
Randomisation protocol[a]	0	2	2	2	0	0	0	-	-	-	-	-
Allocation protocol[b]	0	1	1	1	0	0	0	-	-	-	-	-
Measurement protocol[b]	0	0	0	0	0	0	1	0	0	1	1	0
Assessment of treatment expectations[b]	0	1	0	1	0	1	1	0	0	0	0	0
Justification of outcomes[a]	2	2	2	0	2	1	2	2	2	2	2	2
Validity of outcomes[a]	2	2	2	1	2	1	2	2	2	2	2	2
Reliability and sensitivity of outcomes[a]	2	2	2	1	2	1	2	2	2	2	2	2
Follow-up period[b]	1	1	1	1	1	1	1	1	1	1	1	1
Power calculation[b]	1	1	1	1	1	0	0	1	0	1	1	0
Sufficient sample size[b]	1	1	0	1	1	0	1	1	1	1	1	1
Adequate data analysis[b]	1	1	1	1	1	1	0	1	1	1	1	1
Adequate summary	1	1	1	0	1	0	1	1	1	1	0	1

statistics[b]												
Intention to treat analysis[b]	0	1	1	1	0	0	0	0	0	1	0	1
Control group[a]	1	1	1	1	1	0	0	-	-	-	-	-
Totals												
Total treatment quality (9)	8	7	5	3	3	4	8	4	4	3	3	7
Total study design quality (26)	18	23	22	16	19	12	16	-	-	-	-	-
Total study design quality for non-RCTs (22)	-	-	-	-	-	-	-	16	13	18	16	16
Total quality (35)	26	30	27	19	22	16	24	-	-	-	-	-
Total quality for non-RCTs (31)	-	-	-	-	-	-	-	20	17	21	19	23

[a]0= Inadequate fulfilment; 1= Partial fulfilment; 2= Adequate fulfilment
[b]0=Inadequate fulfilment; 1=Adequate fulfilment

3.3 Overall outcomes

3.3.1 Randomised Controlled Trials

Seven of the included studies evaluated the effectiveness of PMPs through a randomised controlled trial. Of these, five studies [14,28,61,68,76] evaluated the impact of PMPs upon depression. Two of these studies found depression to be significantly reduced at follow-up, one at 12 months [76] and the other at 24 months [28]. Another found a significant improvement post-intervention, but this advantage was lost at long-term follow-up [61]. The final two studies found no significant improvement [14,68]. Although two studies support the long-term effectiveness of PMPs in reducing depression, in one study this was no more effective than individual physiotherapy sessions [28]. Williams et al. [76] evaluated the effectiveness of an inpatient and outpatient PMP; both were found to be effective, but the inpatient approach showed significantly greater effectiveness at 12-month follow-up.

One study, described in two publications, evaluated the effectiveness of PMPs upon quality of life. Both studies found quality of life to be significantly improved at 18 months, but this was amongst females only. This effect was equal to a CBT comparison group [25], but at 36-month follow-up the PMP group was found to be significantly superior to both the other groups [24].

Three studies investigated the impact of PMPs upon anxiety related outcomes. Two studies investigated the impact upon general anxiety [61,76], one found no improvement in anxiety [61], while the other found anxiety to be reduced at post-intervention for an inpatient and outpatient PMP. However no data on anxiety were provided from 12-month follow-up. One study investigated the impact upon fear, obsessions and compulsions [68], which found no significant improvements at any time points.

Three studies investigated the role of cognitive processes, such as self-efficacy, in the long-term following a PMP. Ersek et al. [14] investigated the effect of a PMP upon self-efficacy and coping strategies, finding significantly increased use of relaxation,

exercise/stretch and pacing in the PMP group compared to the bibliotherapy group, however these changes were not associated with improvement in outcome measures. Turner-Stokes et al. [61] investigated the impact of a PMP upon sense of control over pain, finding that both the PMP and comparator, an individually delivered PMP, led to significant increases in sense of control over pain, which were maintained at 12 month follow-up. Williams et al. [76] investigated the effect upon self-efficacy, pain-related cognitions and coping strategies, finding improvement in catastrophising, hopelessness, self-efficacy and active coping strategies at 12-month follow-up.

3.3.2 Prospective cohort studies

Five of the included studies evaluated the effectiveness of PMPs through the use of a prospective cohort design. Three studies investigated the effectiveness of PMPs upon depression, finding that significant improvements in depression were maintained at 12- [27], 18- [10] and 36-month [72] follow-up.

One study [72] evaluated the impact of a PMP upon anxiety related to pain, finding that significant improvements were maintained at 36-month follow-up.

Another study, described in two publications [63,64], investigated the impact of a PMP upon health-related quality of life. It was found that physical health related quality of life was significantly improved at post-intervention and 12-month follow-up, however no data were provided in the first publication on quality of life related to mental health [63]. In the second publication, which presented findings from a 24-month follow-up, neither physical nor mental health related quality of life were different from 12-month follow-up, suggesting a maintained improvement in physical health related quality of life. The lack of data on mental health related quality of life in the first publication makes it difficult to draw any conclusions on whether this stability represents maintenance of improvement.

Four studies also investigated the role of cognitive processes alongside outcome measures [10,27,63,72]. De Rooij et al. [10] found significant reductions in catastrophising and emotional representations of pain, which were maintained from post-intervention to 18-

month follow-up, and an increased sense of control of pain at follow-up. Johansson et al. [27] found significant reductions in catastrophising, praying and hoping, and the use of pain behaviours as ways of coping, which were all maintained at 12-month follow-up. Van Hooff et al. [63] found that self-efficacy related to pain was significantly increased following a PMP and was maintained at 12-month follow-up. Unfortunately the second part of this study [64] did not report data on self-efficacy and so it is not clear whether this effect was maintained at 24-month follow-up. Vowles et al. [72] found that significant improvements in depression and anxiety maintained at 36-month follow-up were associated with significant changes in acceptance of pain and values-based action; that is, behaving in a way concordant with values.

3.3.3 Summary

There is a mixed picture of the effectiveness of PMPs in reducing depression and it is difficult to draw conclusions. Of the eight studies that evaluated the impact upon depression, five found a significant improvement that was maintained over a minimum of 12 months. However, one study found initial improvements declined and a further two studies found no significant improvement. The substantial heterogeneity in the type of PMPs (see Appendix B for details of interventions), participants, comparators and outcome measures, alongside the low quality of some included studies, make it difficult to draw firm conclusions. There is therefore a need for further high quality work to understand the long-term effectiveness of PMPs in reducing depression.

Two studies, represented in four publications, evaluated the impact of PMPs upon quality of life, and found significant improvements to be maintained at a minimum of 12 months following the PMP. Although these findings suggest that PMPs have a lasting positive impact upon quality of life, to draw conclusions from two studies would be premature, but highlights the need for quality of life to be regularly evaluated in trials of chronic pain interventions.

Four studies evaluated the effectiveness of PMPs in reducing anxiety. Two of these studies found significant improvements post-intervention, which was maintained in one study at 36-month follow-up [72], but data were not reported from the follow-up time point in the other [76]. Vlaeyen et al. [68] evaluated the effectiveness upon anxiety as measured by the Fear Survey Schedule [77], although this is associated with fear of movement [67], it has not otherwise been validated for use with chronic pain and was designed for anxiety as the primary problem [77]. The second measure used by Vlaeyen et al. [68], the Maudsely Obsessive-Compulsive Inventory (MOCI) [20], measures cognitions related to obsessive-compulsive disorder. The rationale for using the MOCI as an outcome measure is unclear, as although obsessive-compulsive and anxiety disorders are more common in people with chronic pain, this is restricted to a minority of individuals [47,57].

From the four studies investigating changes in cognitive processes, significant changes in self-efficacy, catastrophising, hope, sense of control over pain, pain related cognitions, acceptance and values-based living were associated with positive outcomes following a PMP and were maintained in the long-term.

Of the included studies, one study found significant differences in the responses of males and females, with women responding positively, whilst men showed no significant improvements [25]. No other studies analysed whether males and females responded differently, this is despite a significant trend in a number of other studies suggesting men and women experience pain differently and respond differently to chronic pain interventions [18,62].

Table 3. Outcomes of included studies

Author	Outcome measures	Process measures	Control group (CG)/ comparator	Analyses	Outcome measure results	Process measure results
Ersek (2008) [14]	GDS	MASES, CPCI, CSQ	▪ Participants received two books on self-management of chronic pain	Analysis of covariance	▪ No statistically significant group effects at any time point.	▪ No statistically significant group effects at any time point on MASES or CSQ. ▪ Statistically greater use of relaxation, exercise/stretch and pacing in the PMP group.
Jensen (2001) [25]	SF36	-	▪ Behaviour orientated physical therapy (PT) ▪ Cognitive behavioural therapy (CBT) ▪ Treatment as usual	Analysis of covariance	▪ Non-significant main effect of time for both males and females. ▪ Non-significant interaction of time and group for males and females. ▪ Significant group main effect for females. ▪ Non-significant group main effect for males. ▪ Females in the PMP group had significantly greater improvement post-intervention than females in other groups. ▪ At 18-month FU females in the PMP and CBT group were significantly more improved than females in other groups.	-

Jensen (2005) [24]- Follow-up to Jensen (2001)	SF36	-	▪ Behaviour orientated physical therapy (PT) ▪ Cognitive behavioural therapy (CBT) ▪ Treatment as usual	Analysis of covariance	▪ No analysis was made of male participants due to low response rate of males in the CG. ▪ Females in the PMP group scored significantly higher on the SF36 global scale than the CG.	-
Kaapa (2006) [28]	DS	-	▪ Individual physiotherapy	Analysis of variance	▪ In both groups there was significant improvement in depression, which was maintained at 6-, 12- and 24-month FU. ▪ No significant differences between the two groups at any time point.	-
Turner-Stokes (2003) [61]	BDI, STAI	Control subscale of WHYMPI	▪ Individually delivered PMP	Linear regression, t-tests	▪ Both groups showed significant improvement in depression after treatment, but this regressed to non-significant in the PMP group at 12-month FU. ▪ There were no significant differences between groups in depression and anxiety. ▪ The comparator group showed significant improvement in anxiety, which was maintained at 12-month FU.	▪ Both groups showed significant improvement in control over pain at 12-month FU, with no significant difference between groups.

Vlaeyen (1996) [68]	BDI, MOCI, FSS-III-R		▪ Education only group ▪ Waiting list control (pre- and post-intervention data only)	Analysis of covariance	▪ Post-intervention, no significant differences between groups on BDI or MOCI. ▪ At post-intervention, significant improvement in fear in the education group. ▪ At 12-month FU no significant differences between groups or over time.	
Williams (1996) [76]	BDI, STAI	PSEQ, PCQ, CSQ	▪ Two PMPs, one inpatient and one outpatient, ▪ A waiting list control	Analysis of covariance	▪ At post-intervention there was a significant improvement in BDI and STAI in both PMP groups compared to the WLC, with a significantly greater improvement in the inpatient group. ▪ At 12 month FU significant improvements were found in both PMP groups in the BDI, with significantly greater improvement in the inpatient group.	▪ At post-intervention there was a significant improvement in CSQ-catastrophising, PCQ-hopelessness and PSEQ in both PMP groups compared to the WLC, with a significantly greater improvement in the inpatient group. ▪ At 12-month FU significant improvements were found in both PMP groups in CSQ-catastrophising, PCQ-hopelessness, PSEQ and PCQ-active coping. There was significantly greater improvement in the inpatient PMP group on CSQ-catastrophising.
de Rooij (2014) [10]	BDI-II	CSQ, IPQ-R, DGSS	-	Generalised estimating equations	▪ At post intervention significant improvement on BDI-II. ▪ At 18-month FU significant improvements on BDI-II were maintained.	▪ At post intervention significant decreases in IPQ- emotional representation, IPQ-coherence, CSQ- catastrophising, IPQ-treatment control

						▪ At post-intervention significant increase in CSQ- perceived control and IPQ-timeline. ▪ At 18 month FU significant decrease in IPQ-emotional representation, IPQ-coherence, CSQ-catastrophising and IPQ-treatment control, IPQ-cyclical. ▪ At 18-month FU significant increase in general self-efficacy and IPQ-timeline.
Johansson (1998) [27]	BDI	CSQ	-	Analysis of variance	▪ Significant improvement in depression at 2-month FU and maintained at 12-month FU.	▪ At post-intervention there was significant increase in CSQ-reinterpretation of pain sensations. This regressed and was no longer significant at 2- or 12-month FU. ▪ There were significant decreases in CSQ-praying and hoping, CSQ-catastrophising and CSQ-pain behaviours at all time points.
van Hooff (2010) [63]	SF36-physical component (PC) only	PSEQ	-	Multivariate analysis of variance	▪ Significant main effect of time on SF36-PC.	▪ Significant main effect of time on PSEQ.
van Hooff (2012) [64] - follow-up to	SF36	-	-	t-test	▪ No significant difference between 1- and 2- year FU on either physical or mental health component of SF36.	

van Hooff (2010)						
Vowles (2011) [72]	BCMDI, PASS-20	CPAQ, CPVI	-	Analysis of variance	▪ Significant improvement at 3-month FU in depression and anxiety. ▪ Improvement maintained at 36-month FU in depression and anxiety.	▪ Significant improvement in acceptance, values-based action and values discrepancy at 3-month FU. ▪ Improvement maintained at 36-month FU in acceptance and values discrepancy. ▪ Values-based action was significantly lower than 3-month FU, but was still significantly improved from pre-intervention.

Note: BCMDI- British Columbia Major Depression Inventory [22], BDI- Beck Depression Inventory [5], BDI-II- Beck Depression Inventory II [4], CPAQ- Chronic Pain Acceptance Questionnaire [37], CPVI- Chronic Pain Values Inventory [38], CSQ- Coping Strategies Questionnaire [49], DGSS- Dutch General Self-efficacy Scale [52], DS- The Depression Scale [50], FSS-III-R-Fear Survey Schedule [77], GDS- Geriatric Depression Scale [79], IPQ-R- Illness Perception Questionnaire [44], MASES-Modified Arthritis Self-efficacy Scale [34], MOCI- Maudsley Obsessive Compulisve Inventory [20], PASS-20- Pain Anxiety Symptom Scale-20 [35], PCQ- Pain Cognitions Questionnaire [7], PSEQ- Pain Self-efficacy Questionnaire [46], SF36- The Medical Outcomes Study 36-item Short Form Health Survey [75], STAI- Spielberger State-Trait Anxiety Inventory [55], WHYMPI- West-Haven Yale Multidimensional Pain Inventory [31]

4. Discussion

The aim of this review was to identify, summarise and critique studies of the long-term psychological and quality of life effects of PMPs. A systematic search using six databases revealed 12 records relating to ten unique studies of long-term psychological and quality of life outcomes. However, heterogeneity in terminology limited the effectiveness of the search strategy. Nine of the twelve papers present significant improvements in psychological functioning or quality of life that were maintained at follow-up points ranging from 12 to 36 months. However, there were three studies that did not find improvement following PMPs. Overall, there was very little return to non-significance, with only two studies with significant findings that had reduced to a non-significant level, one in an anxiety outcome measure and the other on a subscale of the Coping Strategies Questionnaire relating to how pain is interpreted.

Psychological and multidisciplinary approaches to chronic pain management are effective in the short-term, with small to moderate effect sizes [13,15,17,42,51]. Previous reviews have been limited by a focus upon short-term outcomes and the stability of these effects over longer periods of time was unclear. Therefore the findings from this review complement this evidence and suggest that the positive impact of multidisciplinary approaches can be maintained in the long-term. However, due to the low quality of some studies these findings must be approached with caution and only conservative conclusions can be made.

A second finding was the identification of significant changes in self-efficacy, catastrophising, hopelessness, sense of control over pain, pain related cognitions, acceptance and values-based action being associated with significant improvements. The presence of these findings is in line with psychological models of chronic pain, such as the fear-avoidance [69] and psychological flexibility [19] models, both of which highlight the central role of cognitions in modifying and maintaining distress and disability. Both models propose that beliefs about pain lead individuals to avoid pain, which prevents adaptation to living

with pain. Psychological interventions therefore seek to change these cognitions about pain through education and graded exposure, such as pacing [69]. The reduction of catastrophising and other pain related cognitions, such as the emotional representation of pain and hopelessness, suggests that these cognitive processes are related to the effectiveness of PMPs, however the direction of this relationship is currently unclear. However, fear-avoidance beliefs have been shown to double the risk of an episode of pain in the next year [32]. The association of increased self-efficacy with decreased depression fits with previous research that has found self-efficacy to be a mediator of the relationship between pain and disability, and depression [2]. Acceptance and values-based action particularly relate to the psychological flexibility model of chronic pain, which is the basis of the use of acceptance and commitment therapy [19]. In this model acceptance, which is defined as the ability to openly embrace unwanted experiences in the pursuit of one's goals, is the therapeutic alternative to avoidance of pain [36]. Acceptance has previously been associated with reductions in pain, disability, depression and anxiety [39].

A third finding of this review was that only one study investigated differences in treatment response by gender, this is despite findings that men and women appear to experience pain in different ways, with women having a lower tolerance for pain and greater ability to discriminate painful sensations [62]. Differential responses have been found to analgesics [62] and psychological approaches to pain management [18,30]. These differences may be due to the role of catastrophising as a mediator of the relationship between gender and experience of pain [29,30]. The lack of consideration of this in included studies reduces the clarity of the relationship between gender and the effectiveness of PMPs. There is a great need for future research to respond to this by analysing male and female participants separately and investigating the differences in pain experience in men and women.

The process variables identified as being associated with improvement following PMPs are in line with both models of chronic pain and the anticipated mechanisms of psychological treatments. However, what is not clear is how these processes relate to one

another. Clearly some of the processes appear to be related. For example questions arise about how self-efficacy in one's ability to manage pain may relate to acceptance of and willingness to experience pain.

The current review was significantly limited by the quality and heterogeneity of studies. The search strategy used, although systematic in design, was ineffective at identifying studies, with the vast majority being identified through review of key papers' reference lists. The explanation for the low sensitivity in identifying relevant papers appears to lie in the heterogeneity of terminology used by authors. For example, Vlaeyen et al. [68] refer to the evaluated intervention as a combined cognitive/educational intervention, with no reference to a pain management programme despite their intervention meeting criteria for being one. A wider search strategy with more search terms would have identified more related studies, but at the cost of many more unrelated records. This approach was taken in Scascighini et al. [51], but this led to identification of 11,457 records, which required reviewing for eligibility. The heterogeneity in terminology represents heterogeneity in interventions, as such the term pain management programme is used as a way of representing multidisciplinary approaches to pain management delivered in groups and underpinned by psychological theory. Although the included studies are unlikely to have been heterogeneous and therefore conclusions must be conservative, this is also a strength of the review as the included studies represent the clinical reality.

Although a meta-analysis would have been statistically possible to conduct, the summation of effect sizes may have obscured the important differences between interventions being evaluated. Further, the inclusion of both randomised controlled studies and prospective cohort studies, which investigate efficacy and effectiveness respectively, means these studies could not be included together in a meta-analysis. Should further studies of higher quality, more detailed reporting and of greater homogeneity be published then further review and meta-analysis would be warranted.

The heterogeneity in terminology and interventions has been mentioned elsewhere [36,43,48] and has been proposed as being a product of the explosion in research within

chronic pain over the past 30 years [36]. This diversity probably reflects the clinical reality of pain management, with services developing to meet the needs of their own patients and therefore brings with it a high degree of external validity to similar populations and clinical services. However, this heterogeneity presents a significant difficulty to researchers attempting to review and synthesise this corpus of research. Recently there have been calls for greater unification in this field [36] and for a dramatic shift in how psychological research is carried out in chronic pain [43]. The findings of this review support both of these recommendations. There is a need for this research to now move from asking whether psychological approaches to chronic pain work and which are best, to asking why and how these approaches work. Only through greater collaboration and consensus between researchers will this be achieved.

4.1.Implications for future research

As outlined earlier, there is a need for significant change in psychological research within chronic pain, with greater consensus between researchers.

Numerous reviews show that psychological and multidisciplinary approaches to chronic pain are effective when judged on a range of outcome measures, including mood, anxiety, social functioning, disability and quality of life [13,15,17,42,51]. This review suggests that these results are stable over time. Recent commentaries on the state of this research suggest that the focus of research must now be on improving psychological approaches through understanding mechanisms of action [36,43]. This review identified a number of processes that were related to improvements in outcome measures, such as reductions in catastrophising and hopelessness and increases in acceptance and self-efficacy. It is critically important that consensus is reached regarding such constructs, without which the relationships between constructs such as catastrophising and acceptance may not be fully understood. Currently a number of processes have been identified as being associated with improvements following psychological and multidisciplinary approaches to chronic pain [6,45,56,73]; it is likely however, that without a unifying model, research on these processes

will diverge, rather than converge. Further systematic reviews, focussed on processes and mechanisms of change, are needed to unify the current research into a coherent model to guide further research.

The effect size of PMPs and psychological approaches to pain management are modest [13,15,17,42,51], therefore there is a need to improve and evolve interventions. However, evolution of current interventions may constrain future development, therefore, rather than improving PMPs perhaps there is a need to consider what other approaches would complement their positive impact. A major development in recent years has been the development of concepts of self-management [3], patient empowerment [74], and in mental health the concept of recovery [23]. These approaches go beyond the application of an intervention and focus on empowering individuals; they therefore challenge the way that individuals with a disability are constructed both by themselves and others. Future research on how empowerment of individuals with chronic pain can be facilitated would help to ensure that psychological approaches to chronic pain move people away from disability and towards enablement. However, there is risk that empowerment through conceptualising patients with greater responsibility that patients may experience self-blame if their condition deteriorates or does not improve. Therefore, it would be important that this was accounted for in developing these approaches.

A final recommendation is that future studies analyse treatment effectiveness in men and women separately, and that research is needed to understand why men and women may respond differently to pain management programmes.

4.2. Implications for clinical practice

This review adds further support to previous reviews of the effectiveness of PMPs, but also highlights that positive effects are maintained in the long-term. This is important to clinical practice as it adds further weight to recommendations of PMPs and psychological treatments of chronic pain [9].

The support that this review gives to processes such as catastrophising, self-efficacy and acceptance highlight the need for psychological treatments to pay particular attention to these processes. These findings suggest that it is important that clinicians are aware of these and psychological models of pain inform their work. For example, it is important that all clinicians, not just those working within PMPs, respond to patients' beliefs about pain that may maintain avoidance. Awareness of these psychological processes may help clinicians to identify those who are at risk of increased distress and disability.

4.3 Conclusions

This review adds more weight to the support for the effectiveness of pain management programmes, highlighting that pain management programmes lead to significant improvements that are generally maintained in the long-term. This review has also identified a number of areas in which psychological chronic pain research can develop. The field has reached a point where greater consensus is needed to ensure future research leads to convergence of ideas and evidence, which will probably focus on why and how psychological approaches to chronic pain are effective.

References

[1] Airaksinen O, Hildebrandt J, Mannion AF, Ursin H, Brox JI, Klaber-Moffett J, Reis S, Zanoli G, Kovacs F, Staal B. European guidelines for the management of chronic non-specific low back pain. : COST B13 Working Group on Guidelines for Chronic Low Back Pain, 2004.

[2] Arnstein P, Caudill M, Mandle CL, Norris A, Beasley R. Self efficacy as a mediator of the relationship between pain intensity, disability and depression in chronic pain patients. Pain 1999;80:483-491.

[3] Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Educ Couns 2002;48:177-187.

[4] Beck AT, Steer RA, Brown GK. Manual for the beck depression inventory The Psychological Corporation. San Antonio, TX 1996.

[5] Beck AT, Ward CH, Mendelson M, Mock J, Erbaugh J. An inventory for measuring depression. Arch Gen Psychiatry 1961;4:561-571.

[6] Biller N, Arnstein P, Caudill MA, Federman CW, Guberman C. Predicting completion of a cognitive-behavioral pain management program by initial measures of a chronic pain patient's readiness for change. Clin J Pain 2000;16:352-359.

[7] Boston K, Pearce S, Richardson P. The pain cognitions questionnaire. J Psychosom Res 1990;34:103-109.

[8] Breivik H, Collett B, Ventafridda V, Cohen R, Gallacher D. Survey of chronic pain in Europe: Prevalence, impact on daily life, and treatment. European Journal of Pain 2006;10:287-333.

[9] British Pain Society. Recommended guidelines for pain management programmes for adults. London: The British Pain Society, 2007.

[10] De Rooij A, De Boer MR, Van Der Leeden M, Roorda LD, Steultjens MPM, Dekker J. Cognitive mechanisms of change in multidisciplinary treatment of patients with chronic widespread pain: a prospective cohort study. J Rehabil Med 2014;46:173-180.

[11] Dworkin RH, Gitlin MJ. Clinical aspects of depression in chronic pain patients. Clin J Pain 1991;7:79-94.

[12] Dworkin RH, Turk DC, Farrar JT, Haythornthwaite JA, Jensen MP, Katz NP, Kerns RD, Stucki G, Allen RR, Bellamy N. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. Pain 2005;113:9-19.

[13] Eccleston C, Williams ACDC, Morley S. Psychological therapies for the management of chronic pain (excluding headache) in adults. Cochrane Database Syst Rev 2012.

[14] Ersek M, Turner JA, Cain KC, Kemp CA. Results of a randomized controlled trial to examine the efficacy of a chronic pain self-management group for older adults [ISRCTN11899548]. Pain 2008;138:29-40.

[15] Flor H, Fydrich T, Turk DC. Efficacy of multidisciplinary pain treatment centers: a meta-analytic review. Pain 1992;49:221-230.

[16] Guzman J, Esmail R, Karjalainen K, Malmivaara A, Irvin E, Bombardier C. Multidisciplinary bio-psycho-social rehabilitation for chronic low-back pain. The Cochrane Library 2006.

[17] Guzman J, Esmail R, Karjalainen K, Malmivaara A, Irvin E, Bombardier C. Multidisciplinary rehabilitation for chronic low back pain: systematic review. BMJ 2001;322:1511-1516.

[18] Hampel P, Graef T, Krohn-Grimberghe B, Tlach L. Effects of gender and cognitive-behavioral management of depressive symptoms on rehabilitation outcome among inpatient orthopedic patients with chronic low back pain: a 1 year longitudinal study. Eur Spine J 2009;18:1867-1880.

[19] Hayes SC, Strosahl KD, Wilson KG. Acceptance and commitment therapy: The process and practice of mindful change. New York, USA: Guilford Press, 2011.

[20] Hodgson RJ, Rachman S. Obsessional-compulsive complaints. Behav Res Ther 1977;15:389-395.

[21] Ioannidis JP. Why most published research findings are false. PLoS medicine 2005;2:e124.

[22] Iverson GL, Remick R. Diagnostic accuracy of the British Columbia Major Depression Inventory. Psychol Rep 2004;95:1241-1247.

[23] Jacobson N, Greenley D. What is recovery? A conceptual model and explication. Psychiatric services 2001;52:482-485.

[24] Jensen IB, Bergström G, Ljungquist T, Bodin L. A 3-year follow-up of a multidisciplinary rehabilitation programme for back and neck pain. Pain 2005;115:273-283.

[25] Jensen IB, Bergström G, Ljungquist T, Bodin L, Nygren ÅL. A randomized controlled component analysis of a behavioral medicine rehabilitation program for chronic spinal pain: are the effects dependent on gender? Pain 2001;91:65-78.

[26] Jensen MP, Turner JA, Romano JM. Changes in beliefs, catastrophizing, and coping are associated with improvement in multidisciplinary pain treatment. J Consult Clin Psychol 2001;69:655-662.

[27] Johansson C, Dahl J, Jannert M, Melin L, Andersson G. Effects of a cognitive-behavioral pain-management program. Behav Res Ther 1998;36:915-930.

[28] Kaapa EH, Frantsi K, Sarna S, Malmivaara A. Multidisciplinary group rehabilitation versus individual physiotherapy for chronic nonspecific low back pain: a randomized trial. Spine (Phila Pa 1976) 2006;31:371-376.

[29] Keefe FJ, Lefebvre JC, Egert JR, Affleck G, Sullivan MJ, Caldwell DS. The relationship of gender to pain, pain behavior, and disability in osteoarthritis patients: the role of catastrophizing. Pain 2000;87:325-334.

[30] Keogh E, McCracken LM, Eccleston C. Do men and women differ in their response to interdisciplinary chronic pain management?. Pain 2005;114:37-46.

[31] Kerns RD, Turk DC, Rudy TE. The west haven-yale multidimensional pain inventory (WHYMPI). Pain 1985;23:345-356.

[32] Linton SJ, Buer N, Vlaeyen J, Hellsing A. Are fear-avoidance beliefs related to the inception of an episode of back pain? A prospective study. Psychol Health 2000;14:1051-1059.

[33] Lorig KR, Holman HR. Self-management education: history, definition, outcomes, and mechanisms. Annals of Behavioral Medicine 2003;26:1-7.

[34] Lorig K, Chastain RL, Ung E, Shoor S, Holman HR. Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis & Rheumatism 1989;32:37-44.

[35] McCracken LM, Dhingra L. A short version of the Pain Anxiety Symptoms Scale (PASS--20): Preliminary development and validity. Pain Research & Management 2002.

[36] McCracken LM, Marin FM. Current and future trends in psychology and chronic pain: time for a change? Pain management 2014;4:113-121.

[37] McCracken LM, Vowles KE, Eccleston C. Acceptance of chronic pain: component analysis and a revised assessment method. Pain 2004;107:159-166.

[38] McCracken LM, Yang S. The role of values in a contextual cognitive-behavioral approach to chronic pain. Pain 2006;123:137-145.

[39] McCracken LM, Eccleston C. Coping or acceptance: what to do about chronic pain? Pain 2003;105:197-204.

[40] McWilliams LA, Cox BJ, Enns MW. Mood and anxiety disorders associated with chronic pain: an examination in a nationally representative sample. Pain 2003;106:127-133.

[41] Moher D, Liberati A, Tetzlaff J, Altman DG. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. Ann Intern Med 2009;151:264-269.

[42] Morley S, Eccleston C, Williams ACDC. Systematic review and meta-analysis of randomized controlled trials of cognitive behaviour therapy and behaviour therapy for chronic pain in adults, excluding headache. Pain 1999;80:1-13.

[43] Morley S, Williams ACDC, Eccleston C. Examining the evidence about psychological treatments for chronic pain: Time for a paradigm shift? Pain 2013;154:1929-1931.

[44] Moss-Morris R, Weinman J, Petrie K, Horne R, Cameron L, Buick D. The revised illness perception questionnaire (IPQ-R). Psychology and health 2002;17:1-16.

[45] Moss-Morris R, Humphrey K, Johnson MH, Petrie KJ. Patients' perceptions of their pain condition across a multidisciplinary pain management program: do they change and if so does it matter? Clin J Pain 2007;23:558-564.

[46] Nicholas M. Self-efficacy and chronic pain. In: Anonymous Annual conference of the British Psychological Society, 1989.

[47] Raphael KG, Janal MN, Nayak S, Schwartz JE, Gallagher RM. Psychiatric comorbidities in a community sample of women with fibromyalgia. Pain 2006;124:117-125.

[48] Roberts AH. All cats are not gray; all pain programs are not alike. Pain 1989;39:368-369.

[49] Rosenstiel AK, Keefe FJ. The use of coping strategies in chronic low back pain patients: relationship to patient characteristics and current adjustment. Pain 1983;17:33-44.

[50] Salokangas R, Poutanen O, Stengård E. Screening for depression in primary care Development and validation of the Depression Scale, a screening instrument for depression. Acta Psychiatr Scand 1995;92:10-16.

[51] Scascighini L, Toma V, Dober-Spielmann S, Sprott H. Multidisciplinary treatment for chronic pain: a systematic review of interventions and outcomes. Rheumatology 2008;47:670-678.

[52] Schwarzer R, Jerusalem M. Generalized self-efficacy scale. Measures in health psychology: A user's portfolio.Causal and control beliefs 1995;1:35-37.

[53] Smith BH, Elliott AM, Chambers WA, Smith WC, Hannaford PC, Penny K. The impact of chronic pain in the community. Fam Pract 2001;18:292-299.

[54] Smith BH, Elliott AM, Hannaford PC. Is chronic pain a distinct diagnosis in primary care? Evidence arising from the Royal College of General Practitioners' Oral Contraception study. Fam Pract 2004;21:66-74.

[55] Spielberger CD, Gorsuch RL, Lushene RE. Manual for the state-trait anxiety inventory. 1970.

[56] Tota-Faucette ME, Gil KM, Williams DA, Keefe FJ, Goli V. The role of family environment and changes in cognitive processes. Clin J Pain 1993;9:115-123.

[57] Tsang A, Von Korff M, Lee S, Alonso J, Karam E, Angermeyer MC, Borges GLG, Bromet EJ, de Girolamo G, de Graaf R. Common chronic pain conditions in developed and developing countries: gender and age differences and comorbidity with depression-anxiety disorders. The journal of pain 2008;9:883-891.

[58] Turk DC. The potential of treatment matching for subgroups of patients with chronic pain: lumping versus splitting. Clin J Pain 2005;21:44-55.

[59] Turk DC, Okifuji A, Turk DC, Okifuji A. Psychological factors in chronic pain: Evolution and revolution. J Consult Clin Psychol 2002;70:678.

[60] Turk DC, Dworkin RH, Allen RR, Bellamy N, Brandenburg N, Carr DB, Cleeland C, Dionne R, Farrar JT, Galer BS. Core outcome domains for chronic pain clinical trials: IMMPACT recommendations. Pain 2003;106:337-345.

[61] Turner-Stokes L, Erkeller-Yuksel F, Miles A, Pincus T, Shipley M, Pearce S. Outpatient cognitive behavioral pain management programs: a randomized comparison of a group-based multidisciplinary versus an individual therapy model. Arch Phys Med Rehabil 2003;84:781-788.

[62] Vallerand AH, Polomano RC. The relationship of gender to pain. Pain Management Nursing 2000;1:8-15.

[63] van Hooff ML, van der Merwe, Johannes D, O'Dowd J, Pavlov PW, Spruit M, de Kleuver M, van Limbeek J. Daily functioning and self-management in patients with chronic low back pain after an intensive cognitive behavioral programme for pain management. European Spine Journal 2010;19:1517-1526.

[64] van Hooff ML, ter Avest W, Horsting PP, O'Dowd J, de Kleuver M, van Lankveld W, van Limbeek J. A short, intensive cognitive behavioral pain management program reduces health-care use in patients with chronic low back pain: Two-year follow-up results of a prospective cohort. European Spine Journal 2012;21:1257-1264.

[65] van Tulder MW, Ostelo R, Vlaeyen JW, Linton SJ, Morley SJ, Assendelft WJ. Behavioral treatment for chronic low back pain: a systematic review within the framework of the Cochrane Back Review Group. Spine 2001;26:270-281.

[66] Veehof MM, Oskam M, Schreurs KMG, Bohlmeijer ET. Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. Pain 2011;152:533-542.

[67] Vlaeyen JW, Kole-Snijders AM, Boeren RG, Van Eek H. Fear of movement/(re) injury in chronic low back pain and its relation to behavioral performance. Pain 1995;62:363-372.

[68] Vlaeyen JWS, Teeken-Gruben NJG, Goossens MEJB, Rutten-van Mölken MPMH, Pelt RAGB, Van Eek H, Heuts PHTG. Cognitive-educational treatment of fibromyalgia: a randomized clinical trial. i. clinical effects. J Rheumatol 1996;23:1237-1245.

[69] Vlaeyen JWS, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. Pain 2000;85:317-332.

[70] Von Korff M, Dworkin SF, Le Resche L. Graded chronic pain status: an epidemiologic evaluation. Pain 1990;40:279-291.

[71] Von Korff M, Wagner EH, Dworkin SF, Saunders KW. Chronic pain and use of ambulatory health care. Psychosom Med 1991;53:61-79.

[72] Vowles KE, McCracken LM, O'Brien JZ. Acceptance and values-based action in chronic pain: a three-year follow-up analysis of treatment effectiveness and process. Behav Res Ther 2011;49:748-755.

[73] Vowles KE, McCracken LM, Eccleston C. Processes of change in treatment for chronic pain: The contributions of pain, acceptance, and catastrophizing. European Journal of Pain 2007;11:779-787.

[74] Wallerstein N. Powerlessness, empowerment, and health: implications for health promotion programs. American journal of health promotion 1992;6:197-205.

[75] Ware Jr JE, Sherbourne CD. The MOS 36-ltem short-form health survey (SF-36): I. Conceptual framework and item selection. Med Care 1992;30:473-483.

[76] Williams ACDC, Richardson PH, Nicholas MK, Pither CE, Harding VR, Ridout KL, Ralphs JA, Richardson IH, Justins DM, Chamberlain J. Inpatient vs. outpatient pain management: results of a randomised controlled trial. Pain 1996;66:13.

[77] Wolpe J, Lang PJ. A fear survey schedule for use in behaviour therapy. Behav Res Ther 1964;2:27-30.

[78] Yates SL, Morley S, Eccleston C, de C. Williams AC. A scale for rating the quality of psychological trials for pain. Pain 2005;117:314-325.

[79] Yesavage JA, Brink T, Rose TL, Lum O, Huang V, Adey M, Leirer VO. Development and validation of a geriatric depression screening scale: a preliminary report. J Psychiatr Res 1983;17:37-49.

The experience of living with chronic pain in the long term following a pain management programme [2,3]

Robin Muir[a], Gundi Kiemle[a], Rebecca Simm[b]

[a]*Department of Clinical Psychology, University of Liverpool, Liverpool, United Kingdom*

[b]*Community Pain Service, Southport and Ormskirk NHS Hospital Trust, Southport*

Corresponding author:

Robin Muir
Department of Clinical Psychology
University of Liverpool
Whelan Building
Brownlow Hill
Liverpool
L69 3GB

rmuir@liv.ac.uk

[2] To be submitted to Psychology and Health (Page limit: 30) (see Appendix C)

[3] This paper as presented here is currently 31 pages in length due to the narrower margins requested for thesis presentation. In Psychology and Health's format this paper conforms to the page limit.

The experience of living with chronic pain in the long term following a pain management programme

Objective: A number of psychological interventions, such as pain management programmes, have been found to be effective in helping individuals to manage and accommodate chronic pain. This paper presents a qualitative analysis of the experience of living with chronic pain following completion of such an intervention. ***Design:*** Eight individuals with chronic pain who had completed a pain management programme 12-36 months previously participated in semi-structured interviews about their experiences of living with chronic pain. ***Methods:*** Analysis of interviews was based upon interpretative phenomenological analysis and focussed on participants' experiences of living with chronic pain post-intervention. ***Results:*** Three master themes were identified: 'living with pain in a social world', 'developing a new attitude to chronic pain' and 'self-management- becoming your own clinician'. ***Conclusion:*** Following psychological interventions, participants experienced difficulties associated with their self-concept, which was related to the social context in which pain and disability occur. Participants experienced development of new attitudes and approaches to chronic pain and finding ways of coping with the difficulties associated with pain. These conclusions are discussed in relation to the literature.

Keywords: chronic pain; pain management; interpretative phenomenological analysis; disability; identity; acceptance;

Introduction

Chronic pain is pain that has lasted for longer than six months, as such it is an umbrella term for a range of painful and persisting presentations and benign conditions (B. H. Smith, Elliott, & Hannaford, 2004). Estimates of prevalence vary between 19-45% of adults, depending on definitions used in epidemiological studies (Breivik, Collett, Ventafridda, Cohen, & Gallacher, 2006; Covinsky, Lindquist, Dunlop, & Yelin, 2009; Konig et al., 2009). Chronic pain has a wide-ranging impact upon individuals' lives, affecting their physical health, social functioning, psychological well-being and daily activity (B. H. Smith et al., 2001). The potential impact upon an individual's life highlights that chronic pain is a

biopsychosocial experience.

Chronic pain has been subject to a number of qualitative studies, particularly focussed on the experience of pain prior to interventions. A common theme of these studies is the changing understanding of the self. At a physical level, individuals describe experiencing their body as separate from themselves, with the body seen as alien and threatening (Hellström, 2001; Osborn & Smith, 2006; Toye et al., 2013). This change in how the relationship between mind and body is understood is a manifestation of the limitations that pain enforces upon individuals; with the body no longer able to respond to the demands the individual places upon it. These limitations are seen as an external threat that imprisons the conceptualised self from being actualised (Hellström, 2001; J. A. Smith & Osborn, 2007; Toye et al., 2013). This difficulty challenges how individuals understand themselves as they can no longer fulfil expectations and roles of their former self. This loss of identity leads individuals to cling to past selves, engaging in activity that often exacerbates pain (J. A. Smith & Osborn, 2007) in an attempt to be who they understand themselves to be and project this to others.

This crisis of identity is not only a process of losing parts of a former identity, but also the adjustment to new identities that may be unwanted and threatening (J. A. Smith & Osborn, 2007). Often this relates to the social context of the individual, for example, those who seek help with chronic pain must adapt to a new identity as a 'pain patient', whether wanted or not. Relationships can become challenging, with individuals experiencing being defined by these new aspects of themselves (Hellström, 2001).

A broad criticism of this qualitative literature relates to the limit of drawing conclusions from studies using small, homogenous samples, therefore it is important that this research is interpreted in the context of studies using different methods and epistemologies (J. A. Smith, 1996). Osborn & Smith (2006) relate the experiences of chronic pain, in particular the challenge to individuals' conceptualised selves, to Pincus and Morley's (2001) concept of enmeshment. This model describes how concepts of self, illness and pain become *enmeshed*, by which they mean that the elements of the schemas representing these concepts

become incorporated into one another through repeated simultaneous activation. The consequence of this is that activation of one schema also activates other schemas. This model was synthesised from a review of cognitive process biases (Pincus & Morley, 2001), and studies have found that the discrepancy between hoped-for selves and actual selves is predictive of disability and depression in both individuals with acute (Vangronsveld, Morley, Peters, Vlaeyen, & Goossens, 2011) and chronic pain (Morley, Davies, & Barton, 2005; Sutherland & Morley, 2008). Further work has shown a stronger relationship in those with chronic pain than healthy controls (Van Ryckeghem et al., 2013). Although Pincus and Morley's (2001) model gives a framework within which the experience of chronic pain can be understood, it decontextualises the individual with little focus on how others' conceptualisations may contribute to the experience of pain and disability, whilst the individual is also cast as experiencing pain passively. Other models, such as the fear-avoidance model of pain (Vlaeyen & Linton, 2000) and psychological flexibility model (Hayes, Strosahl, & Wilson, 2011), suggest a more active role for the individual, who is seen as constructing their experience of pain through their beliefs about pain and disability. The social model of disability (Oliver, 1990) highlights the role that society has in creating disability through oppression and exclusion and it has been argued that a full understanding of disability cannot be gained without a focus upon both the individual and the collective (Hughes & Paterson, 1997).

The development of psychological models of chronic pain, such as the pain enmeshment model (Pincus & Morley, 2001), and the limited improvements associated with biomedical approaches to chronic pain, which tend to be significant but restricted to a minority of individuals (Turk, 2005), have led to increased interest in psychological interventions aimed at altering the processes that underlie pain, distress and disability (Eccleston, Williams, & Morley, 2012). These include cognitive behavioural therapy (Morley & Williams, 2006), acceptance and commitment therapy (Veehof, Oskam, Schreurs, & Bohlmeijer, 2011) and solution-focussed brief therapy (Simm, Iddon, & Barker, 2014).

Pain management programmes (PMPs) are an established interdisciplinary approach to the management of chronic pain (British Pain Society, 2007), involving physical, psychological and social interventions. Professions involved in the provision of such programmes include physicians, physiotherapists, psychologists, and specialist nurses (Stanos, 2012). The aim of these programmes is not to reduce pain, but to improve functioning and quality of life, and such interventions are effective at doing this (British Pain Society, 2007; Eccleston, Williams, & Morley, 2012). In a recently updated Cochrane review of psychological interventions for chronic pain (Eccleston, Williams, & Morley, 2012) it was concluded that interventions have a small positive impact on disability and catastrophising when compared to active controls, but only improvements in disability remained significant at long-term. The focus of this review was on randomised controlled trials, which due to ethical reasons do not regularly evaluate long-term effectiveness. Therefore conclusions about efficacy or effectiveness beyond 12-month follow up could not be drawn. The authors noted that the majority of included studies lacked a rationale for treatment components and highlighted a need to understand *how* psychological interventions help people with chronic pain. This is supported by The British Pain Society's (2007) guidelines on PMPs, which highlight that there is a high level of diversity between programmes. A small number of quantitative outcome studies have focussed on the long-term outcomes, with generally positive psychological and quality of life outcomes that are stable over time (Muir & Kiemle, 2014), but very little is known about the long-term experiences of participants of PMPs post-intervention.

While quantitative research has been limited by follow-up periods of less than 12 months, qualitative research has a focussed upon the experience of pain prior to interventions and as such is limited in its ability to help researchers and clinicians understand the experience of pain beyond this single point in time. Therefore there is a need for research focusing on the experience of pain over time. This is made more pertinent given the life-long nature of chronic pain and that interventions do not always ameliorate pain. A small number of studies have looked at the experience of psychological interventions, one example is a

recent study of the experience of a PMP (Mathias, Parry-Jones, & Huws, 2014), while another qualitative study found themes to be consistent over a two-year period, during which participants received predominately medical management (Snelgrove, Edwards, & Liossi, 2013). There is a real need for research to investigate the experience of chronic pain over the long-term (Osborn & Smith, 2006), which would broaden the understanding of processes of change and adaptation. Therefore the present research aimed to explore the experience of chronic pain in a group of people who had completed a PMP in the 12 to 36 months prior to commencement of the study.

Principal study aim

To explore the experience of living with chronic pain following a pain management programme.

Secondary aims

- To understand how the experience of living with chronic pain has changed in the time since involvement in a pain management programme
- To explore how processes of change have been understood and experienced by participants
- Gain an understanding of how participants' sense of self has changed and what this means to participants
- To explore the experience of interpersonal relationships following involvement in a pain management programme

Method

Semi-structured interviews were conducted with eight participants with chronic pain who had completed a pain management programme 12-36 months prior to their interview. Interviews were analysed using interpretative phenomenological analysis (IPA) (J. A. Smith, 1996).

Procedure

Ethical approval for the study was granted from the National Research Ethics Service (13/NW/0151). The procedure and materials were discussed with a local patient support group to increase the relevance and accessibility of the study to people with chronic pain. In particular they highlighted the need for participants to have the opportunity to discuss how the impact of the interview on their pain could be minimised, such as breaks and freedom to move around.

Informed consent (see Appendices D & E) was obtained at the beginning of participants' interviews, following which demographic information was collected (see Appendix F) and the interview commenced. Six interviews were conducted in participants' homes, with the remaining two taking place in community NHS premises. The researcher conducted all interviews flexibly using a semi-structured interview schedule (see Appendix G) consisting of open-ended questions to guide discussions. The interview schedule was informed by the extant literature and developed in discussion with a patient support group. Interviews began with a broad question on the history of participants' pain, before focussing on more specific areas related to the research questions, including experiences of relationships, identity and the future. Non-directive probe questions were used to prompt participants to reflect on experiences and provide examples of their experiences. Interviews lasted between 56 and 103 minutes, with an average of 74 minutes, and were digitally recorded before being transcribed. The researcher transcribed two of the interviews, with transcribing services used for the others. All identifying information was changed to maintain participants' anonymity and participants were given pseudonyms.

Participants

Inclusion criteria were: completion of an English NHS Foundation Trust's Community Pain Service's PMP in the previous 12-36 months, English speaking and 18 years of age or over. Exclusion criteria were: unable to provide informed consent, unable to converse in English and significantly distressed or at risk of harm to self or others. Potential participants were identified and contacted by the community pain service, which offers PMPs on a regular basis. Twenty-seven invitations were sent out and eight people agreed to take part. Individuals were to contact the research team if they were interested in taking part, participants were then contacted by telephone to discuss involvement and arrange a time to attend for an interview. Eight participants (seven female, one male; mean age 54.3 years; mean pain duration 14 years) agreed to take part, see Table 1 below for participant characteristics.

The sample size was chosen to ensure that it was possible to consider each interview in sufficient depth for an idiographic methodology. Small sample sizes are needed to allow for sufficient analysis of the subtleties and meanings of individuals' experiences, whilst identifying convergence and divergence between participants (J. A. Smith, Flowers, & Larkin, 2009).

Table 1. Participant characteristics (n=8)

Pseudonym	Age	Duration of pain (years)	Primary location of pain	Employment situation
Sarah	56	30	Lower back	Retired
Charlotte	37	7	Lower back	Not currently working
Lillias	54	7	Lower back	Retired
Ruth	58	10	Lower back	Retired
Tina	70	19	Lower back	Retired
Alex (male)	46	21	Lower back	Not currently working
Judy	62	7	Upper and lower back	Retired
Lindsey	51	11	Neck	Working part-time

Pain management programme

The PMP that participants completed is an 8-week programme facilitated by a

multidisciplinary team consisting of physiotherapists, a medical practitioner, an occupational therapist, a clinical psychologist and an assistant psychologist. The programme involves three sessions per week (two exercise sessions lasting one hour each, plus a three hour education session). Groups are limited to 10 patients and delivered within the community.

Education sessions are based on recognised biopsychosocial topics of pain management (British Pain Society, 2007), such as energy management, pain mechanisms and acceptance. The PMP is underpinned by solution-focussed brief therapy (George, Iveson, & Ratner, 1999), and the programme begins with patients identifying their best hopes for the PMP. 'Problem free talk' is introduced early on as a way of encouraging patients to recognise knowledge about them that is not pain dependent. Throughout the programme, staff seek to encourage patients to identify and amplify when things work well. The didactic aspects of the course, i.e. educational sessions and advice giving, is done when it is line with patients' agendas, rather than being prescriptive (see Simm, Iddon & Barker (2014) for a detailed description).

Data analysis

IPA (J. A. Smith, 1996) is an approach to qualitative enquiry that seeks to examine how people make sense of experiences. IPA was developed in an attempt to breach the divide between quantitative approaches, with a positivist focus upon individuals' cognitions, and qualitative methods, such as discourse analysis, with a particular focus on social and cultural influences (J. A. Smith, 2011). IPA's epistemological pluralism, that is, that there are different ways of knowing things, highlights IPA's ability to engage with other forms of knowledge and therefore has the potential to deepen the understanding of phenomena (Larkin, Watts, & Clifton, 2006). For a more detailed outline of the epistemological approach of this paper see Appendix H.

IPA's theoretical roots lie in phenomenology, hermeneutics and idiography. Phenomenology has at its core the goal of understanding experiences and actions in terms of intentions and meanings (J. A. Smith, Flowers, & Larkin, 2009), therefore the first aim of

IPA is to produce a third-person account as close to the participants' experiences as possible. This phenomenological approach is developed with the hermeneutic understanding of phenomenology, which is that experience is a product of interpretation of perception. These interpretations and processes of meaning making are based within the individual's pre-existing understanding of the world. The IPA process of analysis therefore involves a double hermeneutic, i.e. the analysis is the researcher's interpretation of the participants' interpretation of a phenomenon (J. A. Smith, 2011). The second aim of IPA is to present an interpretation of participants' descriptions of their experiences in relation to the context in which the phenomenon occurs (Larkin, Watts, & Clifton, 2006). IPA therefore does not produce a descriptive account of individuals' experiences, but an interpretation of this experience that is influenced by the researcher's experience, familiarity with IPA and beliefs (J. A. Smith, Flowers, & Larkin, 2009). This highlights the need for researchers to continually reflect on these fore-understandings and the potential impact of these upon the research process.

The method of analysis was based upon the process described by Smith, Flowers and Larkin (2009). Each interview was only analysed once analysis of the preceding interview was complete so that each interview was analysed separately. Analysis of each interview began with an initial reading, with the aim to become familiar with the whole of the interview before coding began. The transcript was then re-read whilst exploratory notes, or codes, were made (see Appendix I for an example). Following this, the main subject of the analysis became the exploratory codes themselves that were reviewed and developed into emergent themes, which were then analysed for connections between them. This resulted in a table of master, superordinate and emergent themes (see Appendix J for an example). This process was then repeated for each interview.

After analysis of each interview, cross-case analysis was begun, aided by NVivo 9 software (QSR International, 2010). This process involved bringing together all emergent themes and searching for connections between themes. This led to the development of superordinate and master themes that represented the content of, and connection between,

emergent themes. A table of each master theme and its constituent superordinate and emergent themes was then generated (see Appendix K for an example).

The analytic process involves the refinement of themes at emergent, superordinate and master levels so that the final analysis provides a comprehensive interpretation of participants' accounts that is both informative and easily understandable. As the analytic process develops this can involve the restructuring of concepts and themes. This iterative process can make it difficult at times to see how themes in the final analysis relate to the earlier stages of analysis. This highlights the importance of having a clear audit trail that allows the reader of the final analysis to understand the analytic process.

Reflexive note

As noted above, a critical aspect of IPA involves researchers reflecting on their own fore-understandings of phenomena. A reflective diary was kept throughout the research process, from conceptualisation to final analysis, by the researcher (see Appendix L for an example excerpt). This reflexive note represents this process. To support this reflective process and to increase awareness of biases and reduce their impact the researcher received regular supervision from their supervisor who read all of the transcripts and reviewed and discussed the analyses with the researcher. The supervisor's role was mainly to facilitate reflection upon the research process and curiosity about the analyses, whilst her clinical experience is within physical health, it is not within chronic pain.

The main author has both professional and personal experience of chronic pain and disability, both of which may have impacted upon the analysis. The rationale for this study came from his experience of working with people with chronic pain and an interest in the lives of people with chronic pain after involvement with services, such as PMPs. Specifically, an interest in the experiences of individuals in the long-term, following interventions that do not ameliorate pain, but aim to increase individuals' ability to manage it, drove this project. Potentially this curiosity about change and adaptation may have interacted with the data. In addition, as the researcher has worked clinically with people with

chronic pain and a range of other long-term conditions while completing this work, this may have impacted on how participants' accounts were interpreted.

The researcher also has experience of physical illness through a close family member who has a neurodegenerative disease, through which she experiences chronic pain. It is likely that this experience has led to the researcher's interest in disability and the psychological experience of illness.

It is also possible that the researcher's academic readings impacted upon the interpretation of the data. An example of this occurred regarding the concept of identity, with a concern being that this emerged due to the researcher's reading. However, reflection upon such decisions was helpful to clarify the significant aspects of participants' experiences, which in the case of identity was felt to be an important theme of participants' experiences. This exemplifies the notion of bracketing within IPA, which is based upon Heidegger's concepts of fore-structures and interpretation. Bracketing is seen as a cyclical and dynamic process, whereby the researcher reflects on their interpretations to identify potential biases within the interpretation stemming from their own preconceptions (J. A. Smith, Flowers, & Larkin, 2009).

Results

Table two below presents the master and sub-themes that emerged from the analysis. This is followed by an account of these themes, with supporting quotes.

Table 2. Themes and sub-themes and their prevalence in participants' accounts

Theme	Sub-theme	Sarah	Charlotte	Lillias	Ruth	Tina	Alex	Judy	Lindsey
Living with pain in a social world	Becoming someone else	✓	✓	✓	✓	✓	✓		✓
	Others' understanding of chronic pain and me	✓	✓	✓	✓	✓	✓		✓
	The moral imperative to cope	✓	✓		✓	✓	✓	✓	✓
	Being supported, not dependent	✓	✓	✓	✓	✓	✓	✓	✓
Developing a new attitude to chronic pain	Finding a way to accept pain	✓	✓	✓	✓	✓	✓	✓	✓
	The importance of confidence and hope		✓	✓	✓	✓		✓	✓
Self-management-becoming your own clinician	Being aware or being constantly on guard	✓	✓	✓	✓	✓		✓	✓
	Taking control by adapting	✓			✓	✓		✓	✓
	Feeling responsible for pain and distress		✓	✓		✓	✓	✓	✓

Living with pain in a social world

Becoming someone else

The majority of participants spoke about a changing understanding of themselves that was experienced as being outside of their control, unwanted at times, and frightening:

> I'm falling out of my fingers, you know, she's [old identity] running away, […], I think once she goes, once it goes, it goes altogether, […], it worries me what it would, how it would be like. (Charlotte)

Charlotte's account highlighted the experience of an enforced change in identity that she feels unable to stop or even slow down ('running away'), and the phrase 'once it goes, it goes altogether' suggests a sense that one's former, lifelong identity can simply vanish – as

if the (former) self will simply cease to exist. The analogy suggests desperation to maintain her pre-pain self, but that attempts to do so were futile. This change prevented individuals from expressing who they understood themselves to be. Participants spoke about an old self that was elusive and which pain prevented being realised. There was a sense that participants sought a return to the person they were, but that having pain and the experiences associated with it, such as losses, had irrevocably changed who they were.

> My whole life revolved around who or what I was and what I did […] things that I used to live to do I can't do because they give me emotional pain because I can no longer do them. (Alex)

Participants' accounts suggested a dissonance between identity and their ability to express themselves to others. The limitations brought about by having physical pain have now also resulted in 'emotional pain'. This draws attention to the interpersonal impact of identity change. Participants described how being unable to express their true identity changed interactions with others, and it is painful to note how some of the former self continues to live on, but feels to be imprisoned in a new identity.

> You feel stupid, you know, you feel like you are different, you're not who you were and I'm not who I was because of this, but there is part of me that is still me and I can't, that can't be shown or expressed anymore. (Lindsey)

Others' understanding of chronic pain and me

The dissonance between individuals' self-concepts and how they were able to behave is reflected in other people's conceptualisations of both the individual and their pain. Participants spoke about how others' understanding of their pain was important to how they experience other people.

> I think the most frustrating thing for me is, you know when people will try and label it and they will say to me, "but you must have done something, you must have moved a pot or you must have lifted something heavy". (Lillias)

The difference between Lillias' and others' understandings of pain leads to disagreement, in Lillias' case there is a suggestion she had greater control over her pain than she felt she did and she experienced other people as judging her ability to cope.

Alex recounted how others' construction of his identity was changed by pain; he described his disability leading to broader assumptions about him.

> Because you are in pain it doesn't mean that, you know, you are stupid and you have to explain to people that you are not, you know, there is not something wrong with you. (Alex)

> With pain you know the fact that because you don't see somebody bleeding or writhing on the floor, that because they have no outward signs […] how can they possibly be suffering, you know, in pain without you knowing it. (Alex)

Alex's account suggested he experienced other people as treating him dramatically differently when aware of his pain, including some making assumptions about his (lack of) intelligence due to disability. Other participants spoke about how the invisibility of pain misleads others, who are experienced as not believing the severity of their pain without any physical evidence to see. Either way, whether one's pain is visible or invisible, it feels as though there are negative consequences. However, the desire not just to be seen as one's pain was evident in a number of participants who spoke about avoiding others, particularly when pain was severe. Individuals described others finding it difficult to understand pain, which changed relationships because others could no longer understand them. In this sense pain was experienced as contagious to others. Therefore, to protect others from being exposed to pain's unpleasantness individuals isolated themselves or concealed pain from others.

The moral imperative to cope

The difficulties that participants experienced within relationships appeared to represent participants' broader concerns with the moral repercussions of chronic pain and their place

in society.

> Like my father says to me, "put up and shut up", […], because nobody wants to hear about your bloody pain, you know, they've all got their own problems and their own pains. (Sarah)

The castigation Sarah experienced at not tolerating pain silently reflects the esteem which society pays to those with 'high pain thresholds' and the value of suffering in silence. Furthermore, there is a minimisation of Sarah's pain in the quote above – everyone else has 'their own pains', implying that her pain can't therefore be any worse than anyone else's. The experience of moral judgement led to attempts to maintain functioning, sometimes through unhelpful behaviour that might increase pain, such as over-activity. Through seeking to avoid moral judgement, participants therefore did things that increased pain, making it harder to cope and more likely to be judged for not coping. Through this, participants experienced their own attempts at coping to likely result in failure and to be counter-productive. The experience of moral failure extended to no longer being a part of society.

> They [Job Centre] asked me about whether I had considered working from home, well of course I have, you know, I hate being, I hate having no money, I hate having no social life, I hate being on my own, if I could work, if I could earn money then my life would be completely different. (Alex)

Alex implies that others perceived and judged his functioning as a choice. He seeks in his account to make it clear that he wanted to work and be involved in society, yet he was isolated and cut-off in all areas of his life (work, home, financially, socially), highlighting a concern that he was no longer able to participate in society in the way he would like.

Being supported, but not dependent

Participants spoke about the importance of relationships, but disliking the impact of dependency upon the relationship.

> Interviewer: What's it like having [Husband] being considerate like that?

> Participant: It's lovely but I don't, what's the word, I don't want him to be like my carer […] that's something we've talked about and we are both aware that we keep the husband and wife tag, as he said, "you care because you care, I care because you are my wife". (Judy)

Judy experienced her husband's support as helpful but also as a potential threat to their relationship, changing how they understood their role to one another. This exemplified participants' experience of a fear that pain would predominate their relationships, changing how others understand them and the meaning of relationships. This change in relationships affected how participants understood themselves, this increased dependence being felt as a threat to autonomy and control. In this sense, support from others was seen as putting one's self in a vulnerable position, which was outside of the individuals' self-concept, in Alex's case the identity of disability.

> It changes my, my perception of myself, I don't like to think of myself as being handicapped in any way […] to be seen I suppose as different or to be kind of treated in, even to be treated with kindness […] is hard for me to deal with, I'd rather just people kind of ignore me or, or just treat me normally, you know. (Alex)

Developing a new attitude to chronic pain

Finding a way to accept pain

Participants spoke about accepting the changes that they had experienced in themselves.

> I am more accepting of the fact that I am not who I used to be and you know and I am never going to be who I used to be. (Alex)

Acceptance appeared to be a pragmatic approach to the experience of change. Rather than ignore the negative consequences that pain had led to, acceptance was akin to forgiveness, in that it acknowledged the impact, but did so in the pursuit of improving quality of life and appeared to grow from a realisation that other perspectives and coping strategies did not always help.

> I have a saying that a friend said to me, “save your breath to cool the porridge”, if it’s worth worrying about, worry about it or argue about it, if it’s not, don't bother. (Tina)

Participants’ accounts suggested that it was not acceptance of pain that was important, but rather acceptance of new identities and the limitations imposed by pain. In this sense acceptance could be seen as being part of a process of grief for the lost aspects of the self, but also a coming to terms with a new self and new way of life.

Acceptance appeared to have a dynamic aspect to it, which reflected the dynamic nature of pain. In Charlotte’s case, acceptance was of pain in the present, but not the future, suggesting that individuals’ perspectives on pain were dynamic in the sense that they were affected by events, such as the failure of operations.

> Got to try and see it for what it is, this is the, my life, at the moment, might not be forever, but this is my life at the moment, and make the most, best of that. (Charlotte)

This might also be seen as a functional way of coping, as contemplating the enormity of life in the future with continuing, chronic pain might feel overwhelming. But, hope and acceptance had the potential to be eroded by unfulfilled expectations. For Charlotte, acceptance appeared to be conditional upon her hoped-for the future, when this hoped-for future is perceived as less likely, her acceptance was affected.

> The tunnel is getting longer and the light at the end of it is, is getting dimmer and dimmer and then you have another operation or more injections, or whatever, stuff like that, you’d turn round and say, erm, well it’s just hard to keep being really, really happy. (Charlotte)

Charlotte’s analogy highlighted the seriousness of her current situation and the stark contrast between the brightness of a pain-free life and the darkness of her life at present. The chronicity of her pain feels endless and hope may be fading. This suggested that acceptance might be related to the contrast between what was being grieved for, the brightness of a pain

free life, and the struggle to remain positive within the darkness Charlotte perceived in chronic pain.

The importance of confidence and hope

Hope and confidence were common themes in participants' accounts, although the focus of hope differed between people.

> No matter what the pain is, we might be feeling dreadful for that couple of days, but you know there is going to be a release and you will get back to being ok'ish again. (Lillias)

Hope had an important function to participants, helping them to move forward when pain was worse. In Lillias' case, her hope was built upon a confidence that her pain would reduce. Without such confidence, Judy experienced flare-ups of pain as deterioration and leading her to hopelessness.

> Knowing it won't ever go, this is it and as I say if it was to go a lot worse, I would get locked in that, the really far end of the scale where it's excruciating, how people live like that I really don't know, that's what gets me down. (Judy)

Judy's choice of phrases like 'it won't ever go', 'locked in' and 'excruciating' suggested a fear of being permanently imprisoned by severe pain. In contrast, Ruth's account highlighted the positive role that hope has in her life.

> We have to look forward, cause if we don't, you've got to be optimistic, cause if you don't, life's not worth living is it? (Ruth)

Ruth's use of the phrase 'we have to look forward' represented the important role hope had to participants in bringing meaning to their lives, although her expression 'life's not worth living' betrayed a sense that the flipside of hope was an underlying hopelessness. An optimistic view was an alternative to a looking back at what has happened. This appeared similar to a process of grief, in this sense, Ruth's optimism is similar to recovery following a

loss, in that she is beginning to look forward to the future, rather than focussing on the abilities and roles that she has lost.

Self-management- becoming your own clinician

Being aware or being constantly on guard?

Most participants spoke about an increased consciousness of pain and their body. This awareness was needed to manage pain, but brought with it a dramatic change in experience. Constant anticipation of pain meant the individual was always conscious of pain. Awareness of the body and pain placed the individual in a constant state of alarm, anticipating the potential onset of pain. Awareness was therefore a paradox; while beneficial, as it facilitated better management, it meant the individual constantly paid attention to pain.

> Participant: Today, here, it's about a level three on the Richter scale of pain.
> Interviewer: What, what would be the top and the bottom for your Richter scale?
> Participant: The bottom is two or three which I live with everyday. (Charlotte)

Charlotte's description of a Richter scale for pain highlighted how attention had become an alarm system. It was no longer the medium through which the world was experienced, but a system for protecting the self from an ever present danger. This awareness tainted individuals' lives, with even the slightest of movements having to be assessed and executed with extra awareness.

> I just have to think about things before I do it. I have to think about how I move before I move. 'Cause if you just suddenly turn, you know, sometimes the muscle can just go so easily, pull a muscle. You know, or, even when I'm exercising I'm thinking, "I don't want to do too many of these because my shoulder will kill me when I get out of here". (Ruth)

Ruth's choice of words ('can just go so easily') betrays her sense of her body's fragility, and that the active, coping approach (exercising) to strengthen the body is never without inherent

threats (‘my shoulder will kill me’).

Taking control by adapting

A number of participants spoke about the process of adapting to chronic pain being inherent to better management of pain and improving quality of life. There was a clear sense that the process of adaptation could be challenging, but that adaptation meant being able to engage in valued activities and regain control from pain.

> I can’t walk very far, my leg gives out. So, […] I got this backpack and I got a little folding stool type thing, […] I just walk so far and then my back would go and I just get the little stool out and sit on it. (Sarah)

Participants’ accounts highlighted that adaptation was aimed at regaining personally meaningful activities, but due to the limits of adaptation, prioritisation was needed. In the following quote Judy described how attempting to adapt her work led to a decision to retire.

> One of the things I’m not supposed to have is stress, so that, I said I would like to step down from being supervisor because that was stressful so I became an assistant clerk which was half on the shop floor and then inputting on the computer, which sounded fine but I couldn’t bend up and down, I can if I push myself but I did it for five days, well five half days, and the whole of that weekend I was in bed in absolute agony. (Judy)

Judy’s account highlighted the priority of managing pain, which governs adaptation. Whilst adaptation can be a positive, it could also lead to losses, in Judy’s case, of work and part of her identity. Adaptation could therefore be a process of considering what was important to the individual and what could be sacrificed to achieve better quality of life. Although Judy’s account suggested a conscious process, Lindsey’s description implied this occurred unconsciously.

> I didn’t realise until I attended the pain clinic, I have lots of halfway finished jobs around the house because I used to have everything done in one day and my shopping, the lot, now it can take me weeks to get things done. (Lindsey)

In Lindsey's case, adaptation seemed to focus on adjusting her expectations. Adapting could therefore be seen as a challenge to how one understands their self. In Lindsey's case, adaptation meant she must accommodate and accept new reduced expectations of herself.

Feeling responsible for pain and distress

Although self-management of pain was spoken about as a helpful part of pain management, participants also described some difficulties that centred on the increased level of responsibility they experienced.

> It's disappointed me a bit and it's upset me a bit and I think well is it my fault because I haven't been going to the gym as much or is it because I was going too much and I was trying to do too much, was I trying to prove to myself? (Tina)

Participants' sense of having control over pain led them to feel responsible for increases in pain and even to blame themselves for making their pain worse. In a way perception of control over pain was a reassuring experience to individuals, as it allowed them to feel autonomous. However, this sense of control was achieved through being aware of the limits of pain and not going beyond them; therefore, pain was ultimately in control, as it set the limits. Participants' accounts suggested that increases in pain lead to shame and a sense of being out of control. Alex's account highlighted that self-management can be an enforced way of coping.

> Interviewer: What was it like making difficult choices like that, about not being able to go out and choosing not to do things that you want to?
> Participant: Strangely enough it's not, it kind of isn't a choice, it's more like if you cut your finger it bleeds, you can't stop it from bleeding and it's the same kind of thing, you know, my life has taken a, has gone down a particular way because of just the way that it has and what I don't really see myself as being in control of it. (Alex)

Alex highlighted that the ways he coped with pain were in reaction to the pain, that he

experiences himself as having no choice and no control over the way his life has turned out. Self-management was ultimately a way of reducing the impact of the control that pain had. It is not that the individual has no control, but that they could not control everything and therefore increases in pain would occur. The guilt and shame that individuals experienced when pain increased is perhaps a result of this perception of control.

A further aspect of control and self-management was how an individual knows when to seek support from others, particularly professionals.

> I have had 10s [pain severity] recently, but when it's a10, […], you have to come to hospital and I only, I was at my parents' [house] a fortnight ago, and I, I was, for God knows what reason, I was terrible, it was acute, chronic pain, it was horrific, and my mum and dad wanted to take me to hospital, but I know my body now […] it's not going to make any difference. (Charlotte)

Charlotte contradicted herself, saying that when pain reached a certain level she must seek professional support; however she then said that she knows that professional help wouldn't make a difference. This suggested that dramatic increases in pain might be so severe that an individual becomes motivated to seek support in the hope it will provide relief, but that from experience they know this is unlikely to happen. The confidence that Charlotte had in her ability to self-manage is challenged by the severity of her pain, but equally she did not see that professional help offered her relief. This represented participants' experience of the limits of self-management (and equally, of professional help) and the emotional impact of reaching this limit.

> A really bad flare up and I've rested, I've had, you know, warm baths, I've taken my morphine and still it's not going, it really does drag me down. (Judy)

> When it has a flare up it's horrendous there are times, days, and I think to myself, "if it got stuck in this mode now, I really don't know if I could cope". (Judy)

Discussion

This study set out to explore the experience of living with chronic pain following involvement in a PMP. The main findings were the experience of difficulties related to the conceptualised self within a social context, the development of new attitudes to the experience of chronic pain and difficulties associated with the self-management of chronic pain.

Participants' experiences of dissonance between their self-identity, others' conceptualisations of them, and participant's behaviour, is consistent with previous work (Hellström, 2001; J. A. Smith & Osborn, 2007; Snelgrove & Liossi, 2009) and in particular the enmeshment model of pain (Pincus & Morley, 2001). This experience remains evident over a three-year period in people with chronic pain (Snelgrove, Edwards, & Liossi, 2013). The present study adds to this finding, highlighting that this experience remains following completion of a PMP, as well as the role of others. Living with pain was related to the development of new forms of identity, coping with others' understandings, avoidance of situations that triggered enmeshed schemas, acceptance of current functioning, projection of current coping into the future and increased sense of control of pain through self-management. Previous work validating the enmeshment model has highlighted that distress is related to the perceived unobtainable nature of hoped-for selves (Morley, Davies, & Barton, 2005). Coping strategies, such as self-management, which can provide a sense of control and confidence despite on-going pain, may help to reduce the perception that hoped-for selves are unobtainable. It has been hypothesised and preliminarily supported (McCracken & Gutiérrez-Martínez, 2011) that acceptance underlies positive adaptation to chronic pain. This may be through the development of individuals' confidence in their ability to actualise important aspects of themselves despite pain (McCracken, Carson, Eccleston, & Keefe, 2004), which has been found to be associated with adaptation to pain (Sutherland & Morley, 2008).

Both the enmeshment model and previous qualitative studies highlight the importance of self-concepts; however, these have focussed predominately on the role of the individual. While these are important aspects of the experience of chronic pain, the current study highlights the role that others have in these experiences. Participants' accounts suggest that it is not only how they construct themselves that is important, but also how others and society construct them and how individuals with chronic pain perceive these constructions. Participants described being isolated from a society that is unable to understand and accommodate their disability, stigmatises those that access health and social care services, which leads to a sense of detachment from society and gives chronic pain a moral context. Previous studies have highlighted the importance of how healthcare professionals (Walker, Holloway, & Sofaer, 1999) and the wider public (Holloway, Sofaer-Bennett, & Walker, 2007) understand those with chronic pain, but have not related these experiences to construction of identity. Further research is required to connect these two elements of the experience of chronic pain.

A significant aspect of participants' experiences of chronic pain related to social context, that chronic pain is an unacceptable ailment and devaluing of those that experience disability. There is a commonality of this experience with those diagnosed with mental health problems, such as schizophrenia, and what has been termed the recovery movement (Anthony & Anthony, 2000). The recovery movement is marked by its ethos of social inclusion, hope and empowerment. The findings of the current study suggest that there is a need for broader social policy that supports those with chronic pain. The recovery model may be a way that people with chronic pain can challenge society's conceptualisations of physical disability, in the same way that has been happening for individuals with longer-term mental health problems.

Although self-management appears to have been important to participants in developing their sense of control, participants' accounts highlighted that self-management can lead the individual to feel ashamed when they are unable to control their pain and may also lead to uncertainty about when to seek professional help. Both patients and

professionals may construct responsibility away from the individual as a way of coping with pain (Eccleston, Williams, Amanda, & Rogers, 1997). This highlights that while the movement to conceptualising chronic pain as a biopsychosocial phenomena has increased the scope for patients to become central in their own care, this may undermine a coping strategy of externalising control, potentially leading to shame at 'poor' management by the patient.

Literature on the efficacy and effectiveness of PMPs suggests that these interventions have a small to moderate effect upon psychological functioning (Eccleston, Williams, & Morley, 2012). Participants' accounts seem to reflect this, as can be seen in the presence of themes relating to positive adaptation to living with chronic pain, such as acceptance and taking control through adaptations. Although some participants spoke about the role of the PMP in these experiences, this was not a prevalent theme in their accounts. There appear to be two possibilities for this. Firstly, the interview schedule did not contain questions regarding the impact of the PMP upon experiences as this was felt to be leading; therefore participants may have chosen not to provide an account of this. Secondly, that despite the evidence for the effectiveness of PMPs, participants did not account for change through their involvement in a PMP

Limitations

There are a number of limitations with the present study. Due to the methodology, generalisations cannot be made. However, the findings do help to bridge the gap between different aspects of research, which is currently needed within chronic pain research (Morley, Williams, & Eccleston, 2013).

The involvement of one man in the sample may have introduced unwanted heterogeneity. Evidence does exist of significant differences, with women showing greater improvement following psychological interventions (Hampel, Graef, Krohn-Grimberghe, & Tlach, 2009). However, the analysis of Alex's account of his experiences did not differ significantly from the other participants.

There was also a large amount of diversity in the duration of pain that participants had experienced, ranging from seven to thirty years; it is possible that such diversity might relate to how individuals have adapted to their pain. While this diversity was not purposively achieved, generally IPA studies use homogenous samples (J. A. Smith, Flowers, & Larkin, 2009). The response rate, 29.7%, raises a question regarding response bias. It is possible that higher functioning individuals were more likely to respond and therefore the participants were more likely to give an account that highlighted coping. It is also possible that the process of giving one's account may prompt positive accounts in an avoidance of cognitive dissonance.

Research Implications

Further research is needed to deepen the understanding of adaptation to chronic pain, both in and outside of the context of psychological interventions. Both qualitative and quantitative methodologies would facilitate this and approaches using mixed methods may help to understand the experience of changes in specific psychological processes associated with chronic pain, such as acceptance and development of self-efficacy.

There have recently been calls for greater collaboration between researchers of psychological aspects of pain (McCracken & Marin, 2014; Morley, Williams, & Eccleston, 2013); in particular, it has been recommended that researchers must begin to draw together research findings and theories into a single psychological model. Such work would help to improve on the effectiveness of psychological interventions which, while being significant, are only of small to moderate effect size (Eccleston, Williams, & Morley, 2012). The findings of this study highlight the stability of experiences associated with identity, acceptance and control of pain, whilst also highlighting the important social aspect of these experiences. A future unifying model must account for these experiences.

Clinical Implications

Clinically, there is currently a focus upon self-management (Barlow, Wright, Sheasby,

Turner, & Hainsworth, 2002). Although these participants' accounts suggested that self-management approaches are helpful in coping with pain, they also conveyed a sense that this is a limited approach, which can lead to shame when pain increases. Therefore, clinicians need to be aware that individuals may feel reluctant to disclose difficulties in using self-management techniques, and their reasons why, and that patients may understandably seek additional support when they reach the limits of self-management.

This study also highlights the need for clinicians to be aware of the social context in which their patients live. Experience of pain is affected by others' understanding of pain, therefore there is need to help individuals respond appropriately to unhelpful social interactions. Also related to the social context in which pain is experienced, clinicians should be aware of the impact of society's construction of disability upon people with chronic pain and should actively seek to nurture more progressive, compassionate and inclusive concepts of chronic pain and disability.

Conclusions

In conclusion, for these participants the long-term experience of chronic pain following a PMP is marked by continued difficulties with identity, which are coped with using a variety of strategies. These strategies seemed to be centred on the development of non-enmeshed schemas of the self, functioning and pain through the development of new attitudes to chronic pain and the use of self-management strategies. This research highlights that adaptation to chronic pain may be related to acceptance and development of new identities, which supports the need for further research on mechanisms of change in psychological interventions for chronic pain and of the need for a unifying model of adaptation to chronic pain.

References

Anthony, W. A., & Anthony, W. A. (2000). A recovery-oriented service system: Setting some system level standards. *Psychiatric Rehabilitation Journal, 24*(2), 159.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counselling, 48*(2), 177-187. doi:http://dx.doi.org/10.1016/S0738-3991(02)00032-0

Breivik, H., Collett, B., Ventafridda, V., Cohen, R., & Gallacher, D. (2006). Survey of chronic pain in europe: Prevalence, impact on daily life, and treatment. *European Journal of Pain, 10*(4), 287-333. doi:10.1016/j.ejpain.2005.06.009

British Pain Society. (2007). *Recommended guidelines for pain management programmes for adults*. London: The British Pain Society.

Covinsky, K. E., Lindquist, K., Dunlop, D. D., & Yelin, E. (2009). Pain, functional limitations, and aging. *Journal of the American Geriatrics Society, 57*(9), 1556-1561.

Eccleston, C., Williams, D. C., Amanda, C., & Rogers, W. S. (1997). Patients' and professionals' understandings of the causes of chronic pain: Blame, responsibility and identity protection. *Social Science & Medicine, 45*(5), 699-709.

Eccleston, C., Williams, A., & Morley, S. (2012). Psychological therapies for the management of chronic pain (excluding headache) in adults. *Cochrane Database of Systematic Reviews,* (11)

George, E., Iveson, C., & Ratner, H. (1999). *Problem to solution: Brief therapy with individuals and families*. London, UK: BT Press.

Hampel, P., Graef, T., Krohn-Grimberghe, B., & Tlach, L. (2009). Effects of gender and cognitive-behavioral management of depressive symptoms on rehabilitation outcome among inpatient orthopedic patients with chronic low back pain: A 1 year longitudinal study. *European Spine Journal, 18*(12), 1867-1880. doi:10.1007/s00586-009-1080-z

Hayes, S. C., Strosahl, K. D., & Wilson, K. G. (2011). *Acceptance and commitment therapy: The process and practice of mindful change*. New York, USA: Guilford Press.

Hellström, C. (2001). Temporal dimensions of the self-concept: Entrapped and possible selves in chronic pain. *Psychology and Health, 16*(1), 111-124.

Holloway, I., Sofaer-Bennett, B., & Walker, J. (2007). The stigmatisation of people with chronic back pain. *Disability and Rehabilitation, 29*(18), 1456-1464. doi:10.1080/09638280601107260

Hughes, B., & Paterson, K. (1997). The social model of disability and the disappearing body: Towards a sociology of impairment. *Disability & Society, 12*(3), 325-340.

Konig, H. H., Bernert, S., Angermeyer, M. C., Matschinger, H., Martinez, M., Vilagut, G., . . . ESEMeD/MHEDEA 2000 Investigators. (2009). Comparison of population health status in six european countries: Results of a representative survey using the EQ-5D questionnaire. *Medical Care, 47*(2), 255-261. doi:10.1097/MLR.0b013e318184759e; 10.1097/MLR.0b013e318184759e

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.

Mathias, B., Parry-Jones, B., & Huws, J. C. (2014). Individual experiences of an acceptance-based pain management programme: An interpretative phenomenological analysis. *Psychology & Health, 29*(3), 279-296.

McCracken, L. M., Carson, J. W., Eccleston, C., & Keefe, F. J. (2004). Acceptance and change in the context of chronic pain. *Pain, 109*(1), 4-7.

McCracken, L. M., & Marin, F. M. (2014). Current and future trends in psychology and chronic pain: Time for a change? *Pain Management, 4*(2), 113-121.

McCracken, L. M., & Gutiérrez-Martínez, O. (2011). Processes of change in psychological flexibility in an interdisciplinary group-based treatment for chronic pain based on acceptance and commitment therapy. *Behaviour Research and Therapy, 49*(4), 267-274. doi:http://dx.doi.org/10.1016/j.brat.2011.02.004

Morley, S., Davies, C., & Barton, S. (2005). Possible selves in chronic pain: Self-pain enmeshment, adjustment and acceptance. *Pain, 115*(1), 84-94.

Morley, S., Williams, A., & Eccleston, C. (2013). Examining the evidence about psychological treatments for chronic pain: Time for a paradigm shift? *Pain, 154*(10), 1929-1931.

Morley, S., & Williams, A. C. D. (2006). RCTs of psychological treatments for chronic pain: Progress and challenges. *Pain, 121*(3), 171-172. doi:10.1016/j.pain.2006.01.017

Muir, R., & Kiemle, G. (2014). *A review of the long-term psychological and quality of life effects of pain management programmes.* Manuscript in preparation.

Oliver, M. (1990). *The politics of disablement*. London: Macmillan Education.

Osborn, M., & Smith, J. A. (2006). Living with a body separate from the self. the experience of the body in chronic benign low back pain: An interpretative phenomenological analysis. *Scandinavian Journal of Caring Sciences, 20*(2), 216-222.

Pincus, T., & Morley, S. (2001). Cognitive-processing bias in chronic pain: A review and integration. *Psychological Bulletin, 127*(5), 599-617. doi:10.1037/0033-2909.127.5.599

QSR International. (2010). *Nvivo* (9th ed.). Melbourne, Australia: QSR International.

Simm, R., Iddon, J., & Barker, C. (2014). A community pain service solution-focused pain management programme: Delivery and preliminary outcome data. *British Journal of Pain, 8*(1), 49-56.

Smith, B. H., Elliott, A. M., Chambers, W. A., Smith, W. C., Hannaford, P. C., & Penny, K. (2001). The impact of chronic pain in the community. *Family Practice, 18*(3), 292-299.

Smith, B. H., Elliott, A. M., & Hannaford, P. C. (2004). Is chronic pain a distinct diagnosis in primary care? evidence arising from the royal college of general practitioners' oral contraception study. *Family Practice, 21*(1), 66-74. doi:10.1093/fampra/cmh115

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis*. London, UK: Sage Publications.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*(2), 261-271.

Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27. doi:10.1080/17437199.2010.510659

Smith, J. A., & Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology & Health, 22*(5), 517-534. doi:10.1080/14768320600941756

Snelgrove, S., Edwards, S., & Liossi, C. (2013). A longitudinal study of patients' experiences of chronic low back pain using interpretative phenomenological analysis: Changes and consistencies. *Psychology & Health, 28*(2), 121-138.

Snelgrove, S., & Liossi, C. (2009). An interpretative phenomenological analysis of living with chronic low back pain. *British Journal of Health Psychology, 14*, 735-749. doi:10.1348/135910709X402612

Stanos, S. (2012). Focused review of interdisciplinary pain rehabilitation programs for chronic pain management. *Current Pain and Headache Reports, 16*(2), 147-152. doi:10.1007/s11916-012-0252-4

Sutherland, R., & Morley, S. (2008). Self-pain enmeshment: Future possible selves, sociotropy, autonomy and adjustment to chronic pain. *Pain; Pain, 137*(2), 366-377.

Toye, F., Seers, K., Allcock, N., Briggs, M., Carr, E., Andrews, J., & Barker, K. (2013). Patients' experiences of chronic non-malignant musculoskeletal pain: A qualitative systematic review. *British Journal of General Practice, 63*(617), e829-e841.

Turk, D. C. (2005). The potential of treatment matching for subgroups of patients with chronic pain - lumping versus splitting. *Clinical Journal of Pain, 21*(1), 44-55. doi:10.1097/00002508-200501000-00006

Van Ryckeghem, D. M., De Houwer, J., Van Bockstaele, B., Van Damme, S., De Schryver, M., & Crombez, G. (2013). Implicit associations between pain and self-schema in patients with chronic pain. *Pain; Pain, 154*(12), 2700-2706.

Vangronsveld, K. L., Morley, S., Peters, M. L., Vlaeyen, J. W., & Goossens, M. E. (2011). Psychological changes and the resolution of acute neck pain after a motor vehicle accident. *European Journal of Pain (London, England); European Journal of Pain, 15*(3), 306-312.

Veehof, M. M., Oskam, M., Schreurs, K. M. G., & Bohlmeijer, E. T. (2011). Acceptance-based interventions for the treatment of chronic pain: A systematic review and meta-analysis. *Pain, 152*(3), 533-542. doi:10.1016/j.pain.2010.11.002

Vlaeyen, J. W. S., & Linton, S. J. (2000). Fear-avoidance and its consequences in chronic musculoskeletal pain: A state of the art. *Pain, 85*(3), 317-332. doi:http://dx.doi.org.ezproxy.liv.ac.uk/10.1016/S0304-3959(99)00242-0

Walker, J., Holloway, I., & Sofaer, B. (1999). In the system: The lived experience of chronic back pain from the perspectives of those seeking help from pain clinics. *Pain, 80*(3), 621-628.

Appendices

Appendix A

Author Guidelines: PAIN

Comprehensive Reviews

Comprehensive reviews offer an extensive summary of an important topic, field, discovery, or innovation. Narrative, comprehensive reviews are encouraged where they offer insight across traditional domains, focus on methods and measurement, or introduce conceptual or philosophical direction. Such reviews are discouraged for evidence synthesis or for the summary of research results where meta-analyses are possible. Comprehensive reviews should be well-illustrated with high-quality figures. There is no specific word limit, but reviews longer than 6,000–8,000 words are discouraged.

The manuscript must contain an Abstract (unstructured, 250 words) Introduction, Methods, Results, Discussion, Acknowledgments, and References.

File format should be Microsoft Word, and manuscript pages should be numbered.

Title page. The title page should include the following: (i) complete title (preferably no chemical formulas or arbitrary abbreviations); (ii) full names of all authors; (iii) complete affiliations of all authors; (iv) the number of text pages of the entire manuscript (including pages containing figures and tables) and the actual number of figures and tables; (v) the author to whom correspondence should be sent and this author's complete mailing address, telephone number, fax number, and e-mail address, and, if available, institutional URL.

Acknowledgments. Place acknowledgments at the end of the text before the reference list and specify the following: (1) contributions that need acknowledging but do not justify authorship; (2) acknowledgments of technical help; (3) acknowledgments of financial and material support, specifying the nature of the support; (4) financial arrangements that may represent a possible conflict of interest.

This would also include any of the following arrangements, such as if any of the authors have a financial relationship to the work; have received any government or company grants or research support; are employees of a company; are consultants for a company; are stockholders of the company; are members of a speakers bureau; or have received any other form of financial support.

Conflict of Interest. A Conflict of Interest statement must be included for all manuscripts within the Acknowledgments section. Even if there are no conflicts of interest, please explicitly state this.

References. Cite literature references in the text using bracketed numbers that correspond to the alphabetized and numbered reference list as follows: "Pain is made worse if you hit the already injured site [15]." For multiple references in the text, please use the format [number,number] (with a comma and no spaces). For example: [2,4,28,33].

- All references cited in the text must be listed at the end of the paper. They should be numbered, double spaced, and arranged alphabetically by first author last name.

- All authors must be listed in the references; the use of et al. is not acceptable.

- References must be complete, including initial(s) of author(s) cited, title of paper, journal, year of publication, and volume and page numbers.

- For citations of books, the following uniform sequence should be maintained: author(s), title of article, editor(s), complete title of book, place of publication, publisher, year, and page numbers.

- Journal titles should be abbreviated according to the National Library of Medicine's Index Medicus. Please refer to the NLM website's FAQ on how to find Index Medicus journals: www.nlm.nih.gov/services/aim.html.

- Unpublished data, personal communications, abstracts that cannot be retrieved by casual readers (e.g., meeting abstracts that require logging into a members-only site), and other inaccessible materials should not be listed as references. Unpublished materials may be cited in parentheses within the text.

- For manuscripts containing citations that are in press, authors must have electronic copies immediately available in case reviewers/editors request these materials.

- URLs should be included for all references that are publicly accessible via the Internet.

Examples:

[1] Adams CWM. Neurohistochemistry. Amsterdam: Elsevier, 1965.

[2] Apkarian AV, Bushnell MC, Treede RD, Zubieta JK. Human brain mechanisms of pain perception and regulation in health and disease. Eur J Pain 2005;9:463-84.

[3] Eccles R. Understanding the symptoms of the common cold and influenza. Lancet Infect Dis 2005;5:718-25.

[4] Turner JA. Coping and chronic pain. In: Bond MR, Charlton JE, Woolf CJ, editors. Pain research and clinical management. Proc. VIth World Congress on Pain, Vol. 4. Amsterdam: Elsevier, 1991. pp. 219-227.

Figure legends. Provide each illustration with a title and an explanatory legend. The title should be part of the legend; do not reproduce the title and legend on the figure itself. Legends should appear on a separate page at the end of the manuscript. Each legend should be numbered consecutively with Arabic numerals (i.e., Fig. 1, Fig. 2, etc.), and should begin with the number of the illustration to which they refer. Explain all symbols and abbreviations used in the figure.

Tables. Tables, with their captions and legends, should be intelligible with minimal reference to the text. Tables of numerical data should each be typed (double spaced) on a separate page, numbered in sequence with Arabic numerals (i.e., Table 1, Table 2, etc.), provided with a title/heading, and referred to in the text as Table 1, Table 2, etc. Provide a detailed description of its contents and any footnotes below the body of the table.

Upload figures and tables as separate files.

Systematic Reviews and Meta-Analyses

These review papers rigorously evaluate the research evidence regarding a particular scientific question by systematically identifying all relevant studies, judging their quality, and providing a fair and balanced statement regarding their overall findings.

For more information about what constitutes a good systematic review, see the PRISMA statement (www.prisma-statement.org/index.htm). The review should include a descriptive and succinct title; a structured abstract; an introduction that specifies the purpose of the

review; a methods section that identifies the databases that were searched, search terms used, and inclusion/exclusion criteria for identified articles; an assessment of the validity of reviewed studies; and a summary that includes future directions for studies in this area. Each study mentioned in the review should include the study design, a description of the study population (age range, disease/severity), the dose and duration of each treatment administered, and the data and P values to accompany any valid comparisons). For further information on reviews, see CD Mulrow. The medical review article: State of the science. Ann Intern Med 1987;106:485-8 and AD Oxman et al. User's guide to the medical literature. VI. How to use an overview. Evidence-based medicine working group. JAMA 1994;272:1367-71.

Appendix B

Table displaying intervention details of studies included in review paper

Study	Study aim	Intervention details
Ersek (2008)	Evaluate efficacy of a pain management programme (PMP) against education control condition.	Seven weekly 90- minute group sessions based around self-management principles, including progressive muscle relaxation, range of motion, strengthening, balance exercises, application of heat and cold. Presentations were also given on pacing activities, challenging negative thoughts, dealing with pain flare-ups and setbacks, and pain medicines and complementary therapies. Two nurses and one clinical psychologist facilitated the intervention.
Jensen (2001)	Evaluate the long-term outcomes of a behavioural medicine rehabilitation programme, its two main components and a control group.	All three treatments (behavioural medicine, behaviour-orientated physical therapy and cognitive behavioural therapy groups) had the following features: lasted four weeks, groups of 4-8, involved a physician, included two didactic sessions on psychological aspects of chronic pain, two sessions on ergonomics, two sessions on medical aspects of chronic pain, all included scheduled time to visit work places, with managers and rehabilitation officials invited to participate in the discharge planning session. The behaviour-orientated physical therapy group was carried out on a part time basis, 20 hours per week, and aimed at enhancing physical functioning. Each participant was given an individual programme that included individual goal setting, gradually increasing exercise, aerobic training, relaxation, and body awareness therapy. The CBT group involved 13-14 hours per week and was aimed at improving participants' ability to manage their pain and resume normal activity. It included activity planning, goal-setting, applied relaxation, cognitive coping strategies, imagery, activity pacing, role of vicious cycles, role of significant others and assertion training. The full-time programme involved both the components of the behaviour-orientated physical therapy and cognitive behavioural therapy treatments.

Jensen (2005) - Follow-up to Jensen (2001)	To evaluate 3-year outcomes of an MDT rehabilitation programme, its two main components and a control group.	See Jensen (2001) above.
Kaapa (2006)	Evaluate effectiveness of an outpatient multidisciplinary rehabilitation programme compared with individual physiotherapy.	Groups of 6-8 patients aimed at improving skills self-management of pain. Programme run by a physiotherapist, two occupational therapists, a psychologist and a physician. Involved 70 hours of rehabilitation, including an intensive five-day period (six hours per day), home-training over two weeks and a semi-intensive period over five weeks (four hours, twice a week). The intervention consisted of cognitive-behavioural stress management, relaxation, back school education and physical exercise.
Turner-Stokes (2003)	Compare individually delivered pain management with group based PMPs.	Groups of 8-10 people, meeting one afternoon per week. The programme included input from psychology, physiotherapy, occupational therapy, and medical staff. Participants were taught about Relaxation, cognitive coping strategies, exercise, pacing and goal setting. Participants were given homework tasks between sessions and written handouts summarising the skills taught each week.
Vlaeyen (1996)	Evaluate the effectiveness of an outpatient educational-cognitive group treatment for patients with fibromyalgia.	Groups of six participants meeting 12 times over six weeks. The educational component of the intervention involved 12 two-hour sessions covering psychosocial factors of fibromyalgia, ergonomic activity, and information about chronic pain in general. Each session ended with physical exercise, such as swimming or cycling. The cognitive treatment involved 12 ninety-minute sessions and aimed to decrease distorted pain attributions and increase self-efficacy expectations. The cognitive treatment was delivered by a psychologist and focussed on using relaxation techniques to understand the role of cognitions in chronic pain.
Williams (1996)	Comparison of inpatient and outpatient PMPs.	An anaesthetist, two psychologists, a physiotherapist, an occupational therapist, and a senior nurse staffed the programmes. Main components of both treatments were: exercise and stretch, goal setting, pacing, education on pain, cognitive and behavioural sessions, drug reduction, relaxation, relapse prevention, and sleep management. The inpatient and outpatient programmes did not differ in content. Inpatients were eon the programme for four weeks, four and a half days a week, and returned home at weekends. The outpatient programme was carried out over eight weeks, three and half hours per week.

de Rooij (2014)	Evaluate cognitive mechanisms of change associated with PMPs.	The PMP was a CBT-based multidisciplinary programme. Participants received education on neurophysiology, goal setting, structuring of daily activities, pacing, ergonomics, relaxation, assertiveness, and physical training. The group met for seven hours per week over two sessions each week, for seven weeks and there were also individual sessions available.
Johansson (1998)	Evaluate the long-term outcomes of a PMP.	PMP staffed by physiotherapists, a physician, a psychologist, an occupational therapist, a gym instructor, a nurse and a vocational counsellor. The PMP was conducted over four weeks, five full days per week, with booster sessions at two months. Each group contained ten participants, with approximately half living at the hospital due to distance from their homes. The intervention involved education on pain, risk factors and coping, sleep, obesity, time management, goal setting, medications, relaxation, graded activity, exercise and pacing. Participants were also taught about cognitive coping skills, including: distraction, imagery and positive coping statements, social skills training and assertiveness.
van Hooff (2010)	Evaluate the one-year follow-up results of a PMP.	Team consisting of a psychologist, a physiotherapist and occupational therapist. Spinal surgeons completed assessments to ensure medical suitability. The programme involved a ten-day group residential programme, with two follow-up days, at one month and one year. The intervention involved 100 hours of contact time, 50 hours of cognitive behavioural training aimed at understanding the link between beliefs, fears, thoughts and mood upon pain. Thirty-five hours was given of graded physical activity and the remaining fifteen hours were used for education on self-management of pain.
van Hooff (2012) - follow-up to van Hooff (2010)	Evaluate the stability of the two-year FU results of a PMP.	See van Hooff (2010) above.
Vowles (2011)	Analyse long-term treatment outcomes and investigate treatment process variables of a PMP.	Interdisciplinary (clinical psychology, physiotherapy, occupational therapy, nursing, medicine) 3-4 week inpatient intervention, with 6.5 hours daily, including 2.25 hours of physical exercise, one hour upon the psychological components on chronic pain, and 30 minutes of mindfulness per day. The remaining time was spent on education on general health.

Appendix C

Author Guidelines: Psychology and Health

1. General guidelines

Manuscripts are accepted in English. British English spelling and punctuation are preferred. Please use single quotation marks, except where 'a quotation is "within" a quotation'. Long quotations of 40 words or more should be indented without quotation marks.

A typical manuscript will not exceed 30 pages including tables, references, captions and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Abstracts of 200 words are required for all manuscripts submitted. If using a structured abstract the primary headings should be: Objective, Design, Main Outcome Measures, Results, Conclusion.

Each manuscript should have 3 to 6 keywords.

Search engine optimization (SEO) is a means of making your article more visible to anyone who might be looking for it. Please consult our guidance here.

Section headings should be concise.

All authors of a manuscript should include their full names, affiliations, postal addresses, telephone numbers and email addresses on the cover page of the manuscript. One author should be identified as the corresponding author. Please give the affiliation where the research was conducted. If any of the named co-authors moves affiliation during the peer review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after the manuscript is accepted. Please note that the email address of the corresponding author will normally be displayed in the article PDF (depending on the journal style) and the online article.

All persons who have a reasonable claim to authorship must be named in the manuscript as co-authors; the corresponding author must be authorized by all co-authors to act as an agent on their behalf in all matters pertaining to publication of the manuscript, and the order of names should be agreed by all authors.

Biographical notes on contributors are not required for this journal.

Please supply all details required by any funding and grant-awarding bodies as an Acknowledgement on the title page of the manuscript, in a separate paragraph, as follows:

For single agency grants: "This work was supported by the [Funding Agency] under Grant [number xxxx]."

For multiple agency grants: "This work was supported by the [Funding Agency 1] under Grant [number xxxx]; [Funding Agency 2] under Grant [number xxxx]; and [Funding

Agency 3] under Grant [number xxxx]."

Authors must also incorporate a Disclosure Statement which will acknowledge any financial interest or benefit they have arising from the direct applications of their research.

For all manuscripts non-discriminatory language is mandatory. Sexist or racist terms must not be used.

Authors must adhere to SI units. Units are not italicised.

When using a word which is or is asserted to be a proprietary term or trade mark, authors must use the symbol ® or TM.

Reports of statistical tests should include an indication of effect size whenever possible. Reports of randomised controlled trials should state any registration details of the trial and should follow CONSORT guidelines where relevant (see Moher, D., Schulz, K.F. & Altman, D.G. for the CONSORT group, 2001. The CONSORT statement: Revised recommendations for improving the quality of reports of parallel-group randomized trials. Annals of Internal Medicine, 134, 657-662).

2. Style guidelines

3. Journal's reference style

APA (6th Ed) referencing style.

5. Figures

Please provide the highest quality figure format possible. Please be sure that all imported scanned material is scanned at the appropriate resolution: 1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour.

Figures must be saved separate to text. Please do not embed figures in the manuscript file.

Files should be saved as one of the following formats: TIFF (tagged image file format), PostScript or EPS (encapsulated PostScript), and should contain all the necessary font information and the source file of the application (e.g. CorelDraw/Mac, CorelDraw/PC).

All figures must be numbered in the order in which they appear in the manuscript (e.g. Figure 1, Figure 2). In multi-part figures, each part should be labeled (e.g. Figure 1(a), Figure 1(b)).

Figure captions must be saved separately, as part of the file containing the complete text of the manuscript, and numbered correspondingly.

The filename for a graphic should be descriptive of the graphic, e.g. Figure1, Figure2a.

Appendix D

Consent Form

Title of Project: The experience of living with chronic pain in the long term following a pain management programme: an interpretive phenomenological analysis.

Name of Researchers:

Mr Robin Muir, Principal Researcher

Dr. Gundi Kiemle, Chief Investigator

Dr. Becky Simm, Local Collaborator

	Please initial all boxes
1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.	☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.	☐
3. I agree that quotations from the interview can be used in the academic manuscript and publications resulting from this research. Quotations will be anonymised and will be changed so that participants cannot be identified from these quoatations.	☐
4. I agree to take part in the above study.	☐

Name of Participant	Date	Signature
Name of Person taking consent.	Date	Signature

Appendix E

Participant information sheet

Project title

The experience of living with chronic pain in the long term following a pain management programme: an interpretive phenomenological analysis.

Research team

Mr Robin Muir, Principal Researcher & Trainee Clinical Psychologist, University of Liverpool

Dr. Gundi Kiemle, Chief Investigator, Senior University Clinical Teacher & Consultant Clinical Psychologist , University of Liverpool

Dr. Becky Simm, Local Collaborator & Principal Clinical Psychologist, Southport and Ormskirk NHS Hospital Trust

Introduction

You are invited to take part in research on the experience of living with chronic pain after completing a pain management programme. This information sheet should provide you with information about this research. Please read the information below as part of considering taking part. Talking about your involvement in is an important part of deciding whether to take part or not. You may have as much time as you need to ask questions about this research before reaching a decision.

Information on the research

Chronic pain can affect many aspects of life, such as physical and emotional wellbeing. People with chronic pain can find it difficult to do things that they used to be able to do, like spending time with family or friends, or working. These difficulties can change the way people feel about themselves and other people. As there is no known cure for chronic pain, treatments involve learning to manage pain. This often means learning how to minimise the impact pain has. Pain management programmes aim to increase people's ability to manage their pain.

Research has shown that, for some people, pain management programmes lead to improvements in physical, emotional and social wellbeing. This research was with people

who had recently finished pain management programmes. There is very little research looking at the experiences and needs of people a year or more after having completed a pain management programme. The aim of this study is to look at what it is like for people to live with chronic pain after attending a pain management programme. This may help to identify important issues that this this group of people face. Identifying these issues may help to develop services to meet this group's needs.

Who can take part?

People may take part if they meet the following criteria:

- Have completed the Southport and Ormskirk Hospital NHS Trust Community Pain service Pain Management Programme 12- 36 months ago.
- Be over 16 years of age
- Continue to experience chronic pain
- Are able to converse in English

What will happen if I participate?

Participants will take part in an interview with a member of the research team. The aim of the interview is for participants to describe their experience of living with chronic pain. This will involve describing important aspects of living with chronic pain, such as important events and difficulties participants have faced. Participants will take part in only one interview, lasting approximately one to two hours. So that participants can manage any pain they experience, they will be able to take breaks and move around. Interviews will be audio recorded so that the interview can be transcribed.

The interviews will be analysed by the research team to identify similarities and differences between participants. This process will identify important aspects of what it is like to live with chronic pain after having attended a pain management programme.

Where will the interview take place?

The researcher can meet participants either at their home or at the Department of Clinical Health Psychology's offices, Curzon Rd, Southport. Participants will be reimbursed for travel if they choose not to be interviewed at home; this will be at the rate of public transport.

Participants who choose to have their interview out with their home will have access to facilities for their comfort, such as drinking water, tea and coffee.

Benefits of taking part

Participants may benefit from thinking about their experience of living with chronic pain. This may help them to understand their pain, the challenges they face and their ways of managing their pain. Participants may also value the opportunity to be involved in research that may contribute to the development of better services for people with chronic pain. Participation will give participants the opportunity to share their experiences and view of living with chronic pain with an audience who value the input of service users. Feedback on the findings of the study will be offered to all participants, which may increase their understanding of themselves in relation to experiencing chronic pain.

Risks

There is a risk that the length of interview may make it difficult for participants to manage their chronic pain, particularly if they need to change position frequently. Before the interview begins, all participants will have the opportunity to discuss taking breaks and changing position with the researcher. The research team are aware that people with chronic pain may experience difficulties concentrating, become thirsty or have other needs that need to be considered when planning the interview. Participants will have the opportunity to discuss their needs with the researcher before consenting and beginning the interview.

As the interview may involve talking about sensitive topics there is the possibility that participants may become upset or distressed. All participants will be able to pause, take breaks or stop the interview if they do not wish to continue. Participants will not be expected to discuss any topics which they are not comfortable talking about. Participants will be given information about organisations they can contact for support, if they feel this is needed, in coping with any distress they experience.

As described below, under the heading 'Confidentiality', there is a risk that confidentiality could be breached if the researcher believed that either the participant or another person were at risk of significant harm. Before doing this, the researcher, where possible, would discuss this with the participant. This could involve contacting a third party, such as the participant's GP, the Police or Social Services.

Confidentiality

Information will be removed from the transcribed interviews that could be used to identify people who have taken part in the study. The information collected from participants will be treated confidentially. Information collected from participants, such as written consent forms or contact information, will be kept separate from the transcribed interview to prevent identification of participants. Audio recordings of interviews will be stored securely at the University of Liverpool and will be destroyed following transcription of the interviews. Electronic files containing information generated from this study will be stored on the University of Liverpool's secure computer network and each file will be password protected.

Dr. Gundi Kiemle, Data Custodian and Senior University Clinical Teacher, University of Liverpool, will retain electronic copies of the interview transcripts, consent forms and demographic information, for 5 years. After 5 years, all information and data generated from this study will be securely destroyed.

The research team has a responsibility to protect participants and others who are known to be at significant risk, from either themselves or others. This means that if the researcher were to believe that somebody was at significant risk of harm, then confidentiality may have to be breached to protect this person(s). If this had to be done then, where possible, this would be discussed with the participant first.

Use of quotes

Quotes from participants' interviews will be used in the academic manuscript and any other publications that result from this study. Quotes will not be used that could identify participants. To ensure confidentiality, information that could identify participants from their quotes will be changed, otherwise the quote will not be used. Individuals will be referred to in publication by a false name to maintain their anonymity and confidentiality. Using quotes helps to support the conclusions of the study and gives a voice to the participants of the research.

Participants' rights

You may decide to stop being a part of the research study at any time without explanation. You have the right to ask that any data you have supplied to that point be withdrawn.

You have the right to refuse to answer or respond to any questions asked of you.

You have the right to have your questions about the procedures answered. If you have any questions about this study, then you can speak with the research team as part of considering participation.

For further information

Mr Robin Muir will be glad to answer your questions about this study and can be contacted by 0151 794 5530 or r.muir@liverpool.ac.uk

For further information regarding this study, the Chief Investigator, Dr. Gundi Kiemle, Senior University Clinical Teacher, can be contacted by 0151 794 5530.

Mrs Lindsay Carter, contact details below, can be contacted regarding complaints or queries regarding this research project.

Lindsay Carter
Clinical Research Governance Manager
University of Liverpool
Research Support Office
2nd Floor Block D Waterhouse Building
3 Brownlow Street
Liverpool L69 3GL
Tel: 0151 794 8722
lindsay.carter@liv.ac.uk

Independent information

The UK Clinical Research Collaboration supports good practice in clinical research to benefit patients. They have a number of booklets about the purpose of clinical research and the benefits and risks of being a participant.

http://www.ukcrc.org/publications/informationbooklets/

Appendix F

Demographic questionnaire

1. Age: ……

2. Gender: ……..

3. Relationship status:

□ Single

□ In a relationship (not cohabitating)

□ In a relationship (cohabitating)

□ Married/ Civil Partnership

□ Divorced

□ Widowed

4. Children:

□ Yes

□ No

If yes:

How many children do you have? …….

How old are your children? .....

Do your children currently live with you?

□ Yes

□ No

5. Employment:

□ Currently working

□ Not currently working

If not currently working,

Please provide details (for example: retired, incapacity benefit,

etc.)……

……

How long since you last worked?.....

6. Duration of chronic pain: ……

7. Location of chronic pain:

……

……

……

8. Would you like to receive feedback on this research? ……..

Appendix G

Interview schedule

- **Can you tell me a brief history of your chronic pain?**
- **How has your life changed since the pain began?**
- **How has your experience of living with chronic pain changed since attending a PMP?**
- **What is it like to experience chronic pain now?**
- **What does experiencing chronic pain mean to you?**
- **How has your sense of self changed since completing a PMP?**
- **How have your relationships with people changed since completing a PMP? This might be relationships with you family, your partner, friends, or others, such as colleagues.**
- **What challenges do you face now that you have completed a PMP?**
- **How does experiencing chronic pain affect how you see the future?**
- **How have your ideas about the future changed throughout your experience of chronic pain?**
- **Is there anything else you would like to talk to me about/ tell me?**

Appendix H

Epistemology of empirical paper

Interpretative phenomenological analysis (IPA) (Smith, 1996) was chosen as the research method due to its epistemological fit with the research questions, which focussed on exploring the experience of participants with chronic pain. IPA has been described as being complementary to research grounded in alternative epistemologies, such as positivist research, with an aim of giving a true and veridical account of phenomena, and other approaches, such as discourse analysis, with a focus on the social and cultural construction of reality (Smith, 1996). IPA was therefore chosen as a way to understand the experience of individuals with chronic pain following involvement in a pain management programme in relation to the current literature on the psychology of chronic pain.

IPA is underpinned by three main theoretical concepts, phenomenology, hermeneutics and idiography.

The first of these, phenomenology, stems from a philosophical movement attributed to the philosopher Edmund Husserl (Smith, Flowers, & Larkin, 2009). The focus of phenomenology is not upon the external world itself, but instead, the individual's experience of the external world. Husserl was interested in understanding the defining or essential qualities of an experience. Husserl believed that through taking a reflexive attitude, i.e. bracketing pre-existing assumptions, one could ascertain the essential aspects of an experience. In the early 20th century Martin Heidegger developed Husserl's conceptualisation of phenomenology. Heidegger argued that as one's understanding and experience of the world is grounded in prior assumptions one cannot transcend these fore-understandings, such that one cannot identify an essential quality of an experience separate from the self (Larkin, Eatough, & Osborn, 2011). Heidegger highlighted that phenomenological enquiry must consider the fore-understandings of the individual and those making the phenomenological enquiry. This conceptualisation of phenomenology highlights

that experience is constructed upon prior knowledge and is therefore an interpretative process or hermeneutic, therefore IPA is in a sense rooted in constructionism (Fade, 2004).

The second principle of IPA, hermeneutics, focuses upon the processes that individuals engage in constructing meaning from their experiences. Heidegger highlighted that the process of meaning-making is grounded in the relationships we have with the world and other people, such that we cannot remove our understanding of ourselves or experience from these relationships (Smith, Flowers, & Larkin, 2009). Similarly, Maurice Merleau-Ponty emphasised that experience is embodied, although individuals tend not to be conscious of the body throughout experience, it is the medium through which the world is explored and therefore is an important aspect of the construction of experience (Merleau-Ponty, 1996). Jean-Paul Sartre's contribution to phenomenology and hermeneutics was to highlight that individuals are continually developing through constructing meaning from experience (Smith, Flowers, & Larkin, 2009). Therefore, in understanding experience we must consider how fore-understandings influence the experience, but also how the experience influences understandings of the world, whilst acknowledging that this is a constant iterative process.

Within IPA hermeneutics relates to both the participants' interpretation of their experiences and the investigator's interpretation of the account provided by participants. This highlights that IPA is a double hermeneutic process whereby the researcher interprets participants' interpretation of experience (Smith, 1996). Hermeneutics shifts researchers' attention away from the descriptive aspect of experience to the contextual meanings of experiences. The process of interpretation aims to go beyond understanding the account of the participant, to what the account may tell us about the participant and what the phenomenon of interest means to them. Underlying this process is the central point that IPA does not seek to uncover a single truth nor does it claim that the presented interpretation is more valid than any another, but rather the analysis facilitates an understanding of participants' experience (Fade, 2004). However, IPA is based on the supposition that although experience is constructed, this is based upon reality. As such, IPA is rooted in critical realism and therefore accepts that there are stable and enduring aspects of reality that

are independent of individuals (Fade, 2004). Fade (2004) captured this well in the following quote, "What is real is not dependent on us, but the exact meaning and nature of reality is" (p. 107).

Finally, as outlined above, individuals' experiences are influenced by prior experience and the world in which they exist, therefore IPA is committed to developing interpretations of experience that are sensitive to both the similarities and differences in participants' accounts. In being sensitive to these, IPA can be described as having an idiographic approach.

In summary, IPA is an approach that is underpinned by a number of philosophical and epistemological concepts (Larkin, Watts, & Clifton, 2006). Studies that use IPA are grounded between a critical realist and contextual constructionivist position (Larkin, Eatough, & Osborn, 2011). IPA therefore has an epistemological openness that acknowledges both that there are things that are real and there is a construction of reality and experience (Michael, 1999).

References

Fade, S. (2004). Using interpretative phenomenological analysis for public health nutrition and dietetic research: A practical guide. *Proceedings of the Nutrition Society, 63*(04), 647-653.

Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.

Larkin, M., Eatough, V., & Osborn, M. (2011). Interpretative phenomenological analysis and embodied, active, situated cognition. *Theory & Psychology, 21*(3), 318-337. doi:10.1177/0959354310377544

Merleau-Ponty, M. (1996). *Phenomenology of perception*. London, UK: Routledge.

Michael, M. (1999). A paradigm shift? connections with other critiques of social constructionism. *Social constructionist psychology* (Nightingale, D.; Cromby, J.; ed.,) Sage.

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis*. London, UK: Sage Publications.

Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health, 11*(2), 261-271.

Appendix I

Example transcript with exploratory notes and coding, participant 1 (Sarah)

Exploratory comments		Original Transcript	Emergent Themes
Everything- emphasis on how special it was.	1	fantastic party, wonderful presents and everything.	
Contrast between her leaving party and loss of colleagues.	2	But just after that it was terrible because I missed the	
	3	camaraderie and I missed my job, I loved my job so	Loss of work/ identity
Weight gain represents severity of depression and loss.	4	much, and I just sunk in to this depression, where I	
Husband took on Sarah's roles.	5	put on about 5 stone. I just like, [husband] would	
Struggle to do everything, 'get out of bed'.	6	drop [youngest son] off at school for me and I'd just	Impact on mood
'Just about'- emphasis on struggle	7	about managed to get my self out of the house and go	Loss of roles
Isolation- contrast with importance of relationships in work	8	up, it's only up the road there, you know, to pick him	
	9	up and I just couldn't be bothered to go out, see	
'Like the end of my life'- loss of work- grief- Did loss of work	10	anybody, do anything, I just, it was just to me like the	Cut off from others-
change relationship with son? Did Sarah feel like a different	11	end of my life, you know. Obviously I had my son,	isolation
mum to other children? Less joy?	12	and when you're depressed [pause] well, you know,	
	13	it's like at the time a mental illness was like a stigma.	Grief/ loss
So different from 'old' self. *Change made it worse- had*	14	And because I'd always been like a jolly person, and	
always been a jolly person.	15	it was just the most horrible feeling in the world, it	
Life felt like nothing- black hole, hopeless. Overwhelmed by	16	was like everyday it was just like getting up and you	Contrast between 'old' and
the challenge of the black hole.	17	just seem to be going into further into this black hole	'new' person
Sarah tried to 'climb' out of the black hole, but was stuck.	18	of nothing and just used to have this feeling that I	
	19	was stuck in this black hole and no matter how much	
	20	I tried I couldn't get to the top of it. I used to say,	
	21	"why am I depressed I've got my husband I've got ,	Insurmountable/
Frustration- 'why?'. Couldn't enjoy motherhood.	22	you know, a little boy. I shouldn't be depressed".	overwhelmed by situation

Can't see why pain and disability would be depressing *Can't explain it?- can she understand it? Feels overwhelming* Two pains, not separate. Hadn't spoken to others. 'But, it was funny'- surprised. *Feels silly now about having felt isolated.* **'Being nutty'- does this help Sarah cope with the experience and talking about mood? Help others to cope with it?** *Sarah did feel entitled to feel depressed, didn't tell others.* Is depression more acceptable or is Sarah more accepting of it? Societal process or interpersonal?	23 24 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	And, erm, what I, eww, it was awful, awful, you just can't explain it because I was in chronic pain everyday but the mental pain was quite often [pause] worse then the, erm, physical pain, but, but it made it worse. It made the mental pain, the psychological pain, made the physical pain much worse you know. But it was funny because once I started talking to my friends and ex-colleagues and things about the, erm, being nutty, I always called them my nutty pills, and it's surprising how many people said, "well, actually I've been on those but I didn't say anything because you know what they're like at work and they'll judge you and they might stop you doing your job". Whereas now, depression and mental illness is much more acceptable in society, isn't it? If that's the right word.	Struggling Difficulty understanding pain Isolated Overcame isolation Humour to protect others and self Impact of pain on others

Note: Underlined-Descriptive coding, **Bold-** linguistic coding, *Italicised*- Conceptual coding

Appendix J

Example theme clustering, participant 1 (Sarah)

Master Theme	Superordinate themes	Emergent theme
Identity	Reconceptualising identity	Redeveloping and recovering self
		Recovering activities
		Connection to 'past' Sarah
		Developing confidence
	Past identity	Identity
		Importance of work
		Loss of activity
		Struggling to get old self back
	Roles and identity	Job= normal
		Role change
		Roles
Social	The role of others	Loss of the PMP
		Shared group experience
		Support of the PMP
		Moaning and groaning
		Others' understandings
		Downward comparison
	Impact of pain on others	Unacceptability of talking about pain
		Humour to protect others
		Managing impact on others
		Impact on others
	Positives of relationships	Relationship as a comfort or resource
		Developing new roles and connections
		Importance of relationships
	Impact of pain on relationships	Change in relationships
		loss of relationships
		Isolation
		Pain forces change
		Solidifying relationships
		Relationships with others
	Being valued and a part of something	Contributing
		Being relied upon
		Being part of something
	Support	Balance of help and independence
		Becoming a burden
		Accepting help
Self-management	Adapting	Appreciative
		Routine and structure
		Acceptance
		Adapting and pragmatic

Appendix K

Example cross case clustering, master theme: psychological adaptation to pain

Table K1. Prevalence of sub-themes

	Sub-theme	
Participant	Acceptance	Confidence in coping and hope for the future
Sarah	✓	
Charlotte	✓	✓
Lillias	✓	✓
Ruth	✓	✓
Tina	✓	✓
Alex	✓	
Judy	✓	✓
Lindsey	✓	✓

Table K2. Sub-theme: Acceptance

Participant	Emergent theme	Example
Sarah	Acceptance	I just think well, acceptance of I can't do it and I do need help and they're not doing it to make me feel bad. They're doing it to make me feel, to help me. I think I've got that off my father, my father's very, the same. He's very independent, erm, even though he's dying now he still finds it difficult to accept, you know, help.
Charlotte	Acceptance of pain now	Seeing if you, see, got to try and see it for what it is, this is the, my life, at the moment [[hmm mmm]] might not be forever, but this is my life at the moment [[hmm mmm]] and make the most, best of that
Lillias	Acceptance of pain	I used to blame it for everything, damn pain, [[right]] but whereas now I am kind of like, it's there [[yeah]] what can I do, I can't change it [[yeah]] it wont go away, live with it and accommodate it but accommodate it in such a way that you're not making yourself ill [[yeah]] just trying to accommodate it you know if you start thinking of too many ways you have just got to sort of roll with it and take each little, in moderation I think [[yeah]] you know not try and be superwoman everyday [[yeah]] that's you isn't it [cleaner], you're superwoman every day aren't you [laughs]
Ruth	Acceptance of limitations	That'd take me an hour [laughs] [[Yeah]] [laughs] you know, if it takes an hour it doesn't matter cause I'm not rushing anywhere

Tina	Acceptance	oh, well, it upsets me a bit, that I can't do what he does, but then I, I have to say to myself, well, you know, he is a man, he is 8 years younger than me [[yes]] and he's fitter than me, so [[yeah, yeah]] he's bound to be able to do more than me [[yeah, yeah]] so you've got to accept the situation, that's the way it is [[yeah, yeah]] I can't expect to do what he does, somebody that's been a rugby player, you know [[yeah, yeah, yeah]] erm, but it does, does get me a bit sometimes
Alex	Acceptance of change	yes well I am more accepting of the fact that I am not who I used to be [[yes]] and you know and I am never going to be who I used to be
Judy	Difficulty of accepting limits of pain	I say my worst problem was I wasn't pacing myself [[hmm]] just being pig headed and thinking I could do everything that I used to.
Lindsey	Acceptance	I don't know I'm just not who, maybe who I could have been, yeah so I think I'll settle to be like this

Table K3. Sub-theme: Confidence in coping and hope for the future

Participant	Emergent theme	Example
Charlotte	Hope for the future	I'm still as, I think we said in the beg, I'm still optimistic [[yeah]] about the future, I'm still going back to it, again, but I'm clinging onto Charlotte, there's still good times, there's [[hmm]] you know, there's still, like, me and [partner] still laugh so much, erm, there's, there is a future, there's, you know, as I, I've said, it's, I'm in it now, but I don't believe, or you've, I think the way you've got to believe is, that I'm not going to be in it forever [[hmm mmm]] it's very difficult to deal with now, Robin, and it's very hard to think that there's, is erm, if the, my future's going to be so bright, I'm going to wear shades, but, erm, it's very hard to think like that, but, I still do
Lillias	Past experience of coping increases confidence	I have sort of tried to go back to the pain that I had when things were really, really dire and thought well ok this is pretty ghastly and I do feel rubbish but it's not as bad as that one is it and you got you know you got, you can do it you can you can I keep comparing them and sort of thinking well you came through that and it's a different pain but you managed it didn't you and you got there [[hmm]] in the end
Ruth	Importance of optimism	it's like now we start again on something fresh, we have to look forward [[OK]] cause if you don't, you've got to be optimistic, cause if you don't, life's not worth living is it?
Tina	Self-confidence	erm, well I suppose, it made me feel better about myself, because, erm, I knew I could do things that I didn't think I could do before [[yeah]] going to the gym and doing all these things

Judy	Feeling hopeless about the future when pain is bad	Knowing it won't ever go [[hmm]] this is it and as I say if it was to go a lot worse, I would get locked in that the really far end of the scale where its excruciating, how people live like that I really don't know [[hmm]] that's what gets me down and the fact that I can't do certain things
Lindsey	Gaining confidence from what you can do	I had a thought, something came to me before and I'd not really thought about it before, you know about the gifts your given, I think mine's listening so I think maybe you know even though I am a bit like this and I can't do like somebody might want to you to go and dig the garden and stuff, I can't do those things, so I can listen.

Appendix L

Excerpts from reflexive diary

Example 1 Thoughts regarding participant following interview

Interview 4- Ruth

Ruth seemed to find it difficult to reflect upon her experiences. It felt difficult at times trying to help her to engage in the reflective process. Ruth seemed to me and spoke about being someone who is fairly introverted and that her normal role in social situations would be to sit and listen to others, rather than taking a more active role. She seemed to struggle at times to articulate herself, perhaps reflecting that she had not put into words some of the ideas she spoke about.

As Ruth appeared nervous about giving her account I was left wondering why she had agreed to take part, it did seem to me somewhat odd that someone who was not at ease with talking openly would want to take part in a process aimed at this. This will be worth considering in analysing her interview as her motivation to participate may relate to her experience.

Ruth appeared to me to seek feedback from myself about the things that she spoke about and I left with a feeling that she wanted confirmation of what she was saying was correct.

The interview left me feeling awkward and I recall being glad to leave Ruth's home. I experienced more anxiety about asking the 'correct' questions as I have in previous interviews. I left with a sense that the interview had not gone as well as I would have liked. Reflecting on this now, I see this as perhaps counter-transference of Ruth's anxiety.

Example 2 Reflections on process of analysis

Regarding trying to be aware of what I bring to the analysis and interpretation, I wonder now if one can be too careful and end up ignoring what they know in an attempt to not "contaminate" the analysis. I can now see that doing this might not be helpful as it is not being reflective, rather just actively ignoring my fore-understandings of the experience of chronic pain. I suppose this is what is meant when people talk about when using IPA you don't bracket as bracketing is not something that is possible, rather the best we can strive to achieve is an awareness of what we bring to the data and reflect on the continuous process of interacting with the data.

Ensuring that the full meaning and depth of meaning is captured in the coding and theming seems to be quite hard. I have found during this analysis that I have found that I have felt unable to capture the full meaning in codes and themes. This strikes me as being in line with the hermeneutic cycle that is spoken of taking place during IPA research. In the coding and theming I feel that an overall meaning is missed, that can only be understood as stemming from the data when the interview is seen as a whole, for example what is meant by hope can only be fully understood when we know what is hoped for and what hope means and this may be contained in another aspect of the interview.

Example 3 Reflection on the concept of identity as a theme

This theme refers to the changes that participants spoke about in terms of their changing understanding of their selves. This is a well documented occurrence with people with chronic pain, having been one of the main themes of Smith and Osborn's (2007) paper,

however, this study appears to highlight the inter-subjective aspect of this experience. I am unsure currently of how I will structure the final analysis, I have some concern that I may over-represent identity if it is presented as a main theme and I do wonder if it's presence in the analysis is a reflection of my own reading on chronic pain. However, what strikes me is the importance of this theme in participants' accounts *and* previous research. Also, the accounts of participants in this study highlighted the inter-subjective nature of identity. I therefore wonder if this aspect of participants' experience would be best presented as part of the master theme relating to the social experience of chronic pain.